POSTTRAUMATIC STRESS AND BEHAVIOR IN INJURED AND SEVERLY ILL INFANTS AND PRESCHOOLERS

Thesis

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Abstract

Objective: Infants and preschoolers comprise a large segment of paediatric patients treated for injuries and severe illness. Due to their developmental stage, infants and preschoolers are particularly prone to unintentional injuries, like burns. Furthermore, there is a peak cancer incidence in early childhood, relative to later childhood and adolescence (Schiestl, Beynon, & Balmer, 2006; Mitter, Michel, Strippoli, Rüegg, & Rebholz, 2011). Both severe injuries and cancer typically require intensive medical treatment and procedures, often followed by long and recurrent periods of hospitalization. The psychological effects of paediatric medical events on children and family members are well established for school-age children and adolescents. Scientific attention on infants and preschoolers has been limited, due to the long-held misconception that young children are not affected or will recover quickly after exposure to distressing situations (Liebermann, Chu, Van Horn, & Harris, 2011). Over the last two decades, a small number of researchers and clinicians has started to work with traumatized young children, mostly children who have witnessed domestic violence or natural disasters, or have been sexually abused (Scheeringa, Zeanah, Drell, & Larrieu, 1995). This research group eventually proposed developmentally-sensitive diagnostic criteria for posttraumatic stress disorder (PTSD), as well as an alternative diagnostic algorithm for PTSD, and facilitated research on early childhood mental health after traumatic experiences. The aim of this thesis was to examine posttraumatic stress and behavioral problems, and individual, medical and family-related predictors in infants and preschoolers with medical experiences like burn injuries and cancer. Prior to this investigation, a detailed literature review of posttraumatic stress disorder (PTSD) and its assessment in infants and preschoolers was conducted. **Methods:** 76 children with burn injuries and 48 children with cancer (age 8-49 months) were assessed, an average of 15 months after their medical diagnosis or injury. Mothers were used as proxy informants for the *Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children* in both patient groups and on the *Child Behavior Checklist* in burn-injured children. Parents were asked to complete questionnaires on individual and family-related characteristics, as well as their own posttraumatic stress symptoms. Medical data on the burn injury sample were retrieved from patient records, whereas medical data for the cancer sample stemmed from questionnaires filled out by attending physicians. **Results:** Overall, 19 children (15.3%) met the age appropriate criteria and algorithm for PTSD proposed by Scheeringa *et al.*, including 10 children (13.2%) with burn injuries and nine children (18.8%) with cancer. However, behavior was found to be

normal in young children with burns. In children with burn injuries, the number of PTSD symptoms was primarily associated with family-related variables like maternal PTSD and quality of family relationships. Higher child age at diagnosis and maternal PTSD increased the risk of full or partial PTSD in children with cancer. **Conclusions:** This thesis provides evidence for a substantial prevalence of PTSD in young children after severe illness or injury and medical treatment. Maternal PTSD consistently emerged as a risk factor for childhood PTSD in both patient groups. Furthermore, children of higher age at diagnosis are at special risk of developing PTSD after cancer is diagnosed. Several implications for clinical care of young pediatric patients with burns and cancer can be drawn from the studies. Paediatricians should be aware of PTSD symptoms and should take a good history for emotional and behavioral problems. In order to minimize traumatic experiences and maximize the continuity of care, it makes sense to: 1) reduce unnecessary exposure to the traumatic elements of the medical condition and its treatment as much as possible (e.g., optimize pain management); 2) increase the child's feelings of security (e.g., by allowing parents to room-in with them, by increasing the predictability and stability of daily routines, by allowing the parent-child dyad some control over aspects of medical treatment wherever possible, and by listening to evaluate each child's understanding of events and possible misconceptions); 3) treat parental distress or PTSD; and 4) address physical health problems as traumatic reminders in the long-term, after treatment ends (e.g., rehabilitative options). Finally, vulnerable children have to be identified as early as possible and linked with specialized mental health services.

Outline of this thesis

The thesis is centred around three research contributions, which all have been published in peer-reviewed journals: a review of posttraumatic stress in early childhood; an empirical study on posttraumatic stress and behaviors in infants and preschoolers with burn injuries; and an empirical study on posttraumatic stress in infants and preschoolers with cancer. The thesis is presented as follows:

Section 1 provides a general introduction, including medical background specific to the issues of study; an overview and synthesis of the existing research literature on psychological consequences of burns and cancer, as well as specific problems concerning the investigation of mental health issues in early childhood; and a description of the theoretical background behind this thesis.

Section 2 contains an overview of posttraumatic stress disorder in infants and preschoolers. It especially focuses on the development of the alternative criteria and diagnostic algorithm for PTSD in young children. This chapter has been published in *Praxis der Kinderpsychologie und Kinderpsychiatrie.*

Graf, A., Irblich, D., & Landolt, M.A. (2008). Posttraumatische Belastungsstörungen bei Säuglingen und Kleinkindern. *Praxis der Kinderpsychologie und Kinderpsychiatrie, 57,* 247-263.

Section 3 outlines the results of an empirical study on PTSD and behavioral problems of young children after burn injuries and has been published in *The Journal of Paediatric Psychology.*

Graf, A., Schiestl., C., & Landolt, M.A. (2011). Posttraumatic stress and behavior problems in infants and toddlers. *Journal of Pediatric Psychology. 36,* 923-931.

In **Section 4**, the results of an empirical study on posttraumatic stress in preschoolers with cancer are presented. This chapter has been accepted for publication in *Psycho Oncology.*

Graf, A., Bergstraesser, E., & Landolt, M.A. (2012). Posttraumatic stress in preschoolers with cancer. *Journal of Psycho Oncology*. Aug 22. Epub ahead of print.

Finally, **Section 5** provides an overall discussion of the findings of this PhD project. After a review of the main findings with reference to existing research, limitations of this research

and directions for future research are described. Finally, the research findings are extrapolated into recommendations for clinical practice.

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General Introduction

1.1 Medical Background

This chapter provides an overview of the epidemiology and nature of burn injuries and cancer and the required medical treatment in children.

1.1.1 Paediatric Burn Injuries

Burns are common paediatric injuries with significant and often life-long consequences. They are defined as injuries to the skin or other tissues caused by thermal trauma, such as scalds (hot liquids), contact burns (hot solids) or flame burns. Injuries from radiation, electricity, friction, chemicals and radioactivity are less common in children, but also count as burns (World Health Organization, 2008).

Epidemiological data on hospitalized children due to burn injuries are limited for Switzerland and other European countries. In the United States, an annual incidence rate of 16.1 per 100’00 children is reported for burn hospitalization (Bowman, Aitken, Maham, & Sharar, 2011). Preschoolers under the age of five years are among the likeliest to be burned, accounting for about 50-80% of paediatric burn injuries, most children suffering scalds or contact burns (Brusselaers, Monstrey, Vogelaers, Hoste, & Blot, 2010). Developmental issues such as curiosity, the impulse to explore their surroundings, and limited motor and cognitive capacities contribute to the elevated risk this age group experiences.

In children, burn injuries are among the leading causes of death, with a global rate of 3.9 deaths per 100'000 children and rates of 0.4 deaths per 100'000 children in high-income countries (World Health Organization, 2008). Despite advances in burn care, burn injuries still cause significant morbidity and disabilities in children, including scarring, disfiguration

and contractures (World Health Organization, 2008). Guideline principles in the clinical care of paediatric burns not only include resuscitation, infection control, surgical wound care and nutrition, but also physical and psychological rehabilitation (Karpelowsky & Rode, 2009).

The severity of burn injuries is commonly determined by the depth and total body surface area (TBSA) damaged (Table 1) (Besner, 2011). The depth of a burn is described in degrees and refers to the skin layers affected (Figure 1).

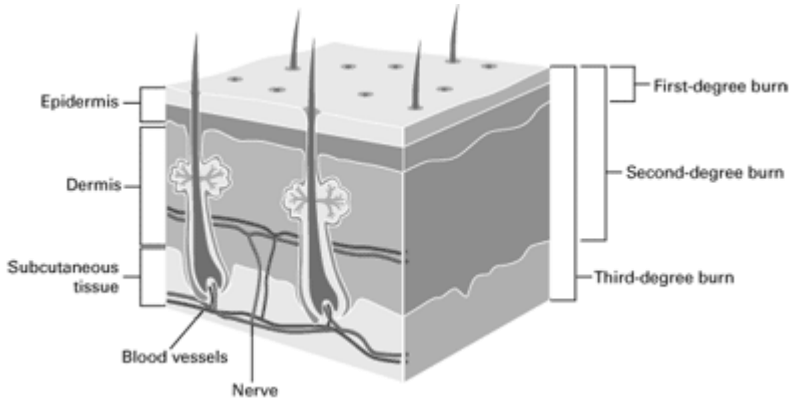

Figure 1 Skin layers (www.columbia-stmarys.org/Types_of_Burn_Injuries)

The ultimate depth and size of the burn might only become evident after several days, since burn wounds are a dynamic, evolving process (Karpelowsky & Rode, 2009).

Table 1 Classification of burn injuries

First-degree (superficial) burns	Restricted to the epidermis Exhibit reddened skin, swelling, no blister formation (e.g., sunburn) Heal spontaneously
Second-degree A (partial thickness) burns	Involve the dermis Are red, with clear blister formation, painful
Second-degree B (partial thickness) burns	Involve the dermis Are white, less painful due to damaged peripheral nerve endings
Third-degree (full thickness) burns	Involve multiple skin layers Have a leathery appearance Are painless due to the destruction of nerve endings

Management of the burned child depends upon the severity of injury. When the size of a burn exceeds 15% to 20% of the total body surface area, the inflammatory response extends beyond the local site of injury and can affect the whole organism. In infants and preschoolers, symptoms of toxic shock may arise when 5-10% of TBSA is affected. A burn injury of 30% TBSA is life-threatening in young children. Blood pressure falls; and if fluids are not administered quickly enough, the child will go into shock and possibly die. Infectious complications are another serious risk, since the barrier to bacteria is broken and the immune system suppressed (Besner, 2011).

Surgical treatment involves the debridement of necrotic tissue. Depending upon the depth of the injury, autologous skin grafting may be required. In young children, skin grafts are often taken from the scalp. If sufficient donor skin is not available, commercial skin substitutes are used to cover the burn. Deep burns initially require daily dressing changes. Dressing changes are usually performed in a bath bed with a mobile shower and consist of three steps: removal of the dressing; showering and debridement; and redressing. All three procedures are painful and often anxiety-provoking (Schiestl & Meuli, 2009)

During the rehabilitation phase, pressure dressings, garments, and splints are employed to minimize scarring. These dressings and garments frequently must be worn for up to a year or longer. Since children tend to form hypertrophic scars and keep growing, they warrant ongoing and prolonged scar management (e.g., reconstructive surgeries, physiotherapy, occupational therapy) (Schiestl et al., 2006).

In conclusion, burn injuries are painful, frightening, and distressing experiences. They often share characteristics of acute medical disorders, as well as chronic illness.

1.1.2 Paediatric Cancer

In children, cancer is a rare but severe disease. It is the second leading cause of childhood mortality in high-income countries, after accidents. In Switzerland, approximately 170 children under the age of 15 years are newly diagnosed with cancer each year. That is an incidence rate of 14.8 children per 100‘000. Incidence is highest among infants less than one year old, with 24.5 cases per 100‘000 persons. Between 1988 und 2007, roughly 37 children died of cancer every year in Switzerland, a mortality rate of 3 children per 100‘000. However, while children diagnosed in the 1980’s had an average survival rate of 68%, mean ten-year

survival has exceeded 82% over the past ten years (Mitter et al., 2011). Improvements in treatment and supportive care, together with the use of large, international trials, have translated into steady improvements in survival rates for most cancer types (Heath & Ross, 2010). However, children with metastatic disease as well as certain subgroups (e.g., infants with leukaemia and high-grade brain tumours) continue to experience poor survival outcomes (Heath & Ross, 2010).

The International Classification of Childhood Cancer (ICCC-3) distinguishes the following main diagnostic groups, in terms of histology and site: most common are leukaemias (34%), central nervous system tumours (18%), and lymphomas (13%) (Bouchardy, Lutz, & Kühni, 2011); but other typical malignancies include neuroblastomas, retinoblastomas, renal tumours, hepatic tumours, malignant bone tumours, soft tissue sarcomas, germ cell tumours, and other malignant epithelial neoplasms. Children diagnosed between the ages of 0 and 4 years old are disproportionally represented, accounting for almost half of cases (46%) (Figure 2).

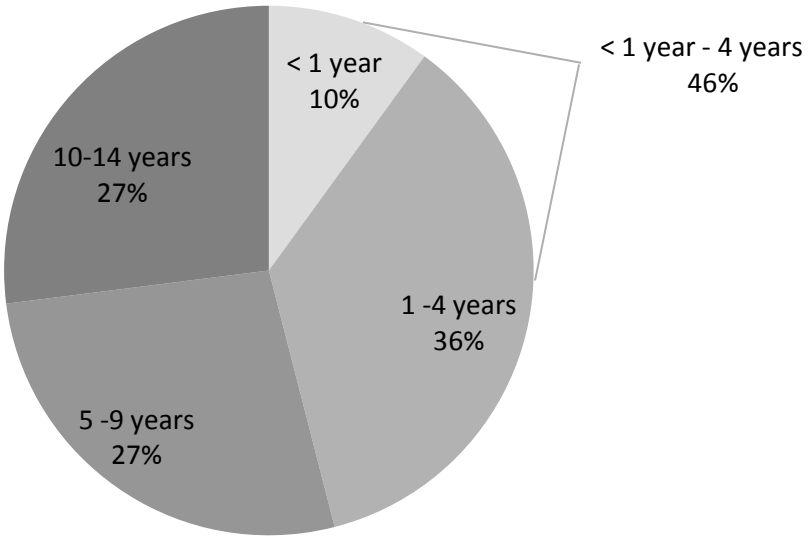

Figure 2 Age at diagnosis between 1976 and 2009 (Swiss Childhood Cancer Registry)

Once cancer is diagnosed, most children are critically ill for the following 2 to 6 months, as treatment is administered. Initial treatment is carried out alternating between hospital stays and outpatient visits, usually requiring 1-3 years before completion, followed by regular check-ups for the next 3-7 years. Medical treatment can include chemotherapy, surgery,

and/or radiation. Depending upon the type and stage of cancer, children also may receive stem or bone marrow transplantations.

Systemic treatment with multi-agent chemotherapy can produce significant and, at times, life-threatening toxicities. Acute side effects like hair loss, nausea and vomiting, depression of the white cell count increasing the risk of life-threatening infections, and oro-intestinal mucositis occur within days to weeks of therapy, and are usually reversible. However, they can cause considerable discomfort and might have a considerable emotional impact. Long-term toxicities can be unique to specific drugs and may have a delayed onset or be irreversible (e.g., cardiotoxicity, peripheral neuropathy, osteoporosis, high-frequency hearing loss, cognitive impairment, second malignancies, etc.). Pain is another common symptom experienced by children with cancer and can occur at the time of diagnosis, as a result of treatment, during anxiety-provoking procedures, and during the terminal phase of the illness. (Widemann & Adamson, 2010).

In summary, in children, as in adults, cancer is a life-threatening event that warrants invasive treatment procedures, the management of side effects, complex treatment regimens for medical care at home, and repeated hospitalisations (Vannatta, Salley, & Gerhardt, 2009).

1.2 Psychological Consequences of Injury and Severe Illness on Children

This chapter first reviews meta-analyses and systematic reviews on psychological adjustment in school-age children after burn injuries and cancer. It then highlights specific problems within the scientific field of mental health in early childhood, specifically focussing on the assessment of mental health problems in this age group. The chapter ends with a review of the small body of research on psychological adjustment in injured and severely ill infants and preschoolers.

1.2.1 State of Research in School-Age Children

As outlined above, medical and surgical advances have markedly improved survival rates and outcomes of paediatric injuries and severe illness. This development has resulted in increased focus on psychological responses to paediatric medical events. Complex treatment regimens often require long-term behavioral changes, and children and family members have to cope

with various stressors during hospitalization, treatment, and the various phases of rehabilitation. Difficulties in psychological adjustment to paediatric physical conditions can be understood as subjective distress and emotional disturbance that can interfere with functioning in school, family and social roles and negatively affect quality of life (Lavigne & Faier-Roumann, 1992). Moreover, injuries and severe illnesses qualify as traumatic stressors when they are frightening or horrifying, threatening the physical integrity or life of oneself or others, and induce experiences of fear, horror and helplessness (American Psychiatric Association, 2000).

Posttraumatic stress symptoms (PTSS) - such as re-experiencing symptoms (intrusive thoughts, dreams, flashbacks), avoidance/numbing symptoms (avoiding reminders of the trauma, emotional numbing, restricted affect, reduced interest) and hyper-arousal symptoms (sleep problems, hyper-vigilance, irritability) are common and considered normal or even adaptive in the early days and weeks after severe paediatric medical events. Certain aspects of traumatic stress reactions may be part of normal psychological recovery, activated in respond to extreme and overwhelming stressors (e.g., they may signal distress and recruit support, process and resolve traumatic memories, or manifest as avoidance so as to tolerate stress or proceed with survival) (Kassam-Adams, 2006). To transition into the psychiatric diagnosis of posttraumatic stress disorder (PTSD), PTSS must induce severe impairment in several domains of daily living and activities, and must persist for more than one month (American Psychiatric Association, 2000). The results of reviews on school-age children consistently demonstrate that PTSS are well-documented sequelae after severe medical illness (Stuber, Shemesh, & Saxe, 2003) and that PTSD is the most commonly established psychiatric disorder in survivors of injuries (Stoddard & Saxe, 2001; Brosbe, Hoefling, & Faust, 2010) and critical illness (Davydow, Richardson, Zatzick, & Katon, 2010). In a meta-analysis considering PTSD in children between the ages of 6 and 19 among multiple injury and illness samples, prevalence rates were estimated to be 19% among injured children and 12% in severely ill children (Kahana, Feeny, Youngstrom, & Drotar, 2006). Among paediatric burn patients, 25% of children present with PTSD (Davydow, Katon, & Zatzick, 2009). Point prevalence rates for cancer-related PTSD in childhood cancer survivors are reported to range from 2% to 21% (Taieb, Moro, Baubet, Revah-Levy, & Flament, 2003; Bruce, 2006).

However, the phenomenology of psychological responses is not limited to PTSS and PTSD. Dealing with intensive paediatric medical events is associated with a range of adjustment and adverse emotional reactions in school-age patients and their family members. In addition to

PTSD, mood, anxiety, and conduct disorders are reported as co-morbid diagnoses following injuries (Stoddard & Saxe, 2001). Clinically-relevant depressive symptoms are reported in about 13% of paediatric burn survivors (Davydow et al., 2009). In children with cancer, a significant minority experiences marked levels of psychological distress, including anxiety and depression (Kurtz & Adams, 2010).

A meta-analysis of risk factors that predict adverse psychological outcomes after different *paediatric injuries* identified threat to life, posttraumatic parental distress, and pre-traumatic emotional and behavioral problems as the strongest predictors of PTSD (Cox, Kenardy, & Hendrikz, 2008). Female gender was a statistically significant predictor, but had weak effect sizes. Further significant predictors were younger age, exposure to earlier trauma, and injury severity. However, statistics indicate that all except pre-traumatic psychopathology and threat to life exhibited some level of inconsistency (Cox et al., 2008). Another meta-analysis identified the following risk factors impacting psychological adjustment in burned school-age children: body location, burn injury variables (e.g., length of hospital stay, medical complications, burn severity, compliance, and pain), parental adjustment, and child pre-traumatic psychological functioning (Noronha & Faust, 2007).

PTSD predictors in *paediatric cancer* patients include female gender, reduced social support and family functioning, and prior stressful life events. Objective trauma characteristics - such as treatment modality and intensity - as well as life threat did not predict PTSD in school-age cancer patients (Bruce, 2006). Furthermore, an elevated risk of psychological maladjustment is reported for children with brain tumours and those requiring intense central nervous system therapy (Patenaude & Kupst, 2005). Maternal PTSD remained an inconclusive predictor (Bruce, 2006).

In summary, the psychological impacts of burn injuries and cancer have received much-deserved research attention. A substantive body of literature reveals significant and persistent psychological sequelae in patients and families. However, the great majority of studies have focussed on school-age children and adolescents, whereas the very youngest patients – infants and preschoolers - have largely been neglected.

1.2.2 Developmental Considerations on Mental Health in Early Childhood

Despite the fact that young children are overrepresented in the paediatric burn and cancer population, understanding of early childhood mental health after intensive medical events lags far behind knowledge of older child and adolescent psychological adjustment (Egger, 2009). For a long time, clinicians and researchers assumed that very young children are not impaired by stressful experiences because they either fail to appreciate them or recover quickly and forget. Furthermore, it was presumed the rapid physical, cognitive, behavioral and emotional development of early childhood period would hinder any valid identification and reliable measurement of psychiatric symptoms. On the backdrop of these concerns, efforts to make current diagnostic classification systems developmentally sensitive were lacking (Egger, 2009).

Before 1992, when the first version of the Child Behavior Checklist (CBCL) appropriate for 2- and 3-year old children was published (Achenbach, 1992), no validated parent-report assessment tools on early childhood emotional and behavioral problems were available. Publication of the first edition of the *Handbook of Infant Mental Health (Zeanah, 1993)* was a milestone, starting to address such issues as whether or not specific types of psychiatric disorder in early childhood can be defined and reliably measured; whether the validity of such syndromes can be substantiated; whether syndromes are transient or stable; and whether syndromes are limited or an indication of future distress and impairment in children (Egger, 2009). Early childhood mental health was then defined as « the young child's capacity to experience, regulate, and express emotions, form close and secure relationships, and explore the environment and learn. All these capacities will be best accomplished within the context of the caregiving environment (…).» (Zeanah & Zeanah, 2009, p. 6). Meanwhile, investigations in the areas of genetics, neuroscience, child development, developmental psychopathology and clinical disorders and their treatment have provided premises to constitute the empirical foundation of infant mental health: 1) early experiences are important for brain development and function; 2) the child-caregiver relationship is the most important context for experiences; 3) healthy development requires ongoing support that focuses on strengths; and 4) infants and preschoolers are capable of developing psychiatric problems that may be enduring (Zeanah & Zeanah, 2009).

From 2000 to 2002, the American Academy of Child and Adolescent Psychiatry sponsored a task force on early childhood mental health, involving researchers with broad clinical and developmental expertise all striving to develop operationalized criteria for a number of

disorders, including PTSD. Their aim to derive clearly-defined diagnostic criteria still was challenged by the following particular characteristics unique to early childhood: 1) The broad range of symptoms secondary to the vast range of cognitive and verbal capacities (e.g., rumination, obsession, guilt). In early childhood, these capacities are still evolving, and it is therefore difficult to determine whether a child is yet able to develop such symptoms. 2) Emerging and evolving capacities might contribute to developmental differences in the clinical expression of symptoms. 3) A young child's self-reporting of symptoms is limited, due to insufficient cognitive and language capacities. Therefore, access to young children's internal feelings, thoughts and experiences is strongly restricted. Meanwhile, reliance on caregiver reports runs the risk of information bias. 4) Investigators and caregivers seem to systematically underestimate the psychopathology in infants and preschoolers. Their smaller body size makes them easier to manage and adults often confound clinical problems with normal developmental disturbances (Task force on research diagnostic criteria: Infancy and preschool, 2003).

Within this process, clinicians and researchers were also concerned with developmental capacities needed to display psychiatric disorders, such as PTSD. In the context of early traumatic experiences, several important developmental capacities must be considered (Scheeringa, 2009). First, in order to be psychologically traumatized by an injury or illness, one must have the capacity to remember that event. There is research evidence that behavioral memory (also called *implicit* or *non-declarative*) starts prenatally. Memories of this type are subconscious and cannot be recalled verbally. However, they may be enacted behaviourally (Howe, Toth, & Cicchetti, 2006). Another type of memory is called *autobiographical*, *explicit* or *declarative memory*. It starts to develop around the age of 18 months with the emergence of language and manifests in a coherent narrative form after 36 months. Discrete experienced events can be recalled verbally (Howe et al., 2006). In summary, preschoolers are able to clearly recall stressful experiences, whereas infants may exhibit behavioral evidence of recalling previous experiences (Scheeringa, 2009).

Another important requirement for PTSD is the capacity to demonstrate fear and/or distress. Children are able to express emotions such as distress, joy, positive feelings and interest within the first few weeks of life (Rosenblum, Dayton, & Muzik, 2009). The so called *primary emotions* of happiness, anger, sadness and fear are all that are manifest until the age of 6-8 months, while self-conscious emotions like shame, guilt and embarrassment begin to appear by 18-21 months (Lewis, 1993). However, the challenge is to identify what is and

what is not frightening for infants and preschoolers. For example, oxygen masks or being left without caregivers can be more distressing for young children than the actual medical procedure (Scheeringa, 2009).

The motor capacity to express posttraumatic stress symptoms through such behaviors as play re-enactment or avoidance usually emerges between 7 and 18 months, whereas talking about thoughts and feelings generally emerges somewhere around 18-29 months (Scheeringa, 2004). Finally, in order to express trauma-related impairment in social relationships, children need to have formed social relationships. Focused attachments are established between 7 and 18 months, at which point separation and stranger anxiety, and secure attachment behavior become evident (Rosenblum et al., 2009).

In summary, the developmental capacities needed for the manifestation of posttraumatic stress symptoms emerge from 9 months of age onwards. Therefore, even infants younger than one year old can present with the emotional and behavioral manifestations of trauma.

1.2.3 Diagnosis of PTSD in Young Children

Considering these specific developmental characteristics and difficulties, the task force devised the *Research Diagnostic Criteria-Preschool Age* (RDC-PA) and subsequently proposed a developmentally-sensitive revision of the diagnostic criteria for preschool children. Their work on PTSD is largely based on the pioneering research of Scheeringa and colleagues, who have demonstrated the poor reliability and validity of the DSM-IV PTSD criteria, leading to the development of an alternative set of PTSD criteria and algorithm (PTSD-AA) (see Table 3, Section 2). These researchers have pointed out that 8 of the 19 diagnostic criteria require the ability to convey thoughts and feelings, both of which are hardly possible for preverbal or barely-verbal children (Scheeringa et al., 1995). The subsequent development of the PTSD-AA includes modified wording of the DSM-IV diagnostic criteria to make symptoms more objective, anchored in observable behaviour and developmentally sensitive to young children (e.g., feelings of detachment or estrangement (C5) “may be manifest in young children as social withdrawal.”). Other changes include the elimination of the A2 criterion, since a child may not be able to report its initial experiences of a traumatic event, and no adult may have been present to witness its reaction. Furthermore, symptoms were removed when considered developmentally inappropriate (e.g., sense of foreshortened future and inability to recall aspects of the trauma). Finally, one of the most

important differences in the PTSD-AA is lowering the threshold of cluster C from three to one symptom (Scheeringa et al., 1995). Since many of the cluster C symptoms are internalizing and abstract phenomena, they are either developmentally impossible or difficult to detect in young children (Scheeringa, Zeanah, & Cohen, 2011). Preliminary research confirms the reliability, as well as the criterion, convergent and discriminant validity of the PTSD-AA among preschool children (Scheeringa, Peebles, Cook, & Zeanah, 2001; Scheeringa, Zeanah, Myers, & Putnam, 2003; Meiser-Stedman, Smith, Glucksman, Yule, & Dalgleish, 2008; De Young, Kenardy, & Cobham, 2011b). Furthermore, PTSD-AA forms the basis for the age-related subtype of PTSD proposed by the DSM-V Task Force (Scheeringa, Zeanah, et al., 2011).

A developmentally-sensitive assessment of PTSD in young children is currently facilitated by two diagnostic interviews. The *Preschool Age Psychiatric Assessment* (PAPA) was the first diagnostic instrument for which psychometric properties were published. Its use is limited to children from 2 to 5 years old (Egger et al., 2006). The *Diagnostic Infant Preschool Assessment* (DIPA) (Scheeringa & Haslett, 2010) represents the most contemporary diagnostic instrument for children ages 1 to 6 years. It is an updated version of the semi-structured interview developed by Scheeringa and Zeanah (2005a). Relative to the PAPA, it is shorter to administer, and contains separate modules and a diagnostic algorithm for each disorder (Scheeringa & Haslett, 2010). In many ways, development of the PTSD-AA and its incorporation into diagnostic instruments has served to enhance initial research on infants and preschoolers, after various traumatic events.

1.2.4 State of Research in Infants and Preschoolers

There is preliminary evidence from studies on trauma reactions in preschoolers after gas explosions, motor vehicle accidents and burn injuries, all applying the PTSD-AA. In the first study, 25% of 3 and 4-year old children met criteria for the three PTSD symptoms clusters six months after a gas explosion at their nursery school. However, the rate of diagnosed full PTSD could not be determined, since the criteria for impairment in daily living were not evaluated (Ohmi et al., 2002). In another study involving a small sample of preschoolers with different injuries, PTSD was diagnosed in 14.3% of the children (Scheeringa, Wright, Hunt, & Zeanah, 2006). Furthermore, 10% of 2 to 6-year old children were diagnosed with PTSD at 6-month follow-up after a road traffic accident (Meiser-Stedman et al., 2008). In the first

study on burn-injured preschoolers, 29% of the children exhibited acute stress symptoms within one month post-burn (Stoddard, Saxe, et al., 2006). The most recent longitudinal study investigating trauma reactions of 1-6 year old unintentionally-burned children identified PTSD prevalence rates of 25% one month post-injury and 10% six months post-injury (De Young, Kenardy, Cobham, & Kimble, 2012).

In contrast, PTSD in infants and preschoolers with severe paediatric illnesses has been completely neglected. Though preschool children have been enrolled in some studies, none of these studies categorized subjects by age (Davydow et al., 2010). Knowledge is reduced to the description of posttraumatic stress symptoms in a single case study of a 5-month-old boy diagnosed with cancer (Roy & Russell, 2000).

Certain risk factors for the development of PTSD in injured preschoolers have been identified in the form of pre-trauma, trauma-related and post-trauma/recovery/environment characteristics. Elevated externalizing problem behaviors pre-trauma increase the risk for the development of PTSD in injured preschoolers (Scheeringa, Wright, et al., 2006). Trauma severity – as indicated by variables like burn size, length of hospital stay, and number of dressing changes - has been correlated with the number of acute stress symptoms in burn-injured preschoolers (Drake et al., 2006). On the other hand, management of pain with higher doses of morphine is associated with fewer PTSD symptoms in preschoolers with burns (Stoddard et al., 2009). As a post-trauma/recovery/environment variable, parent distress seems to mediate the relationship between a child's level of pain and acute stress symptoms one month post-burn (Stoddard, Ronfeldt, et al., 2006).

Additionally to PTSD symptoms, there are investigations on behavioral problems in preschoolers with burn injuries and severe illness. The most recent study on trauma reactions in preschoolers with burn injuries uncovered oppositional defiant disorders (ODD) and separation anxiety disorder (SAD) as the most commonly diagnosed conditions following PTSD (De Young et al., 2012). An earlier study using the Child Behavior Checklist (CBCL) identified significantly more internalizing behaviors in 2 and 3-year old burn survivors relative to healthy controls (Meyer, Robert, Murphy, & Blakeney, 2000). In another prospective study, preschoolers with burn injuries did not appear to have more emotional or behavioral problems post-burn (Kent, King, & Cochrane, 2000). Reasons for these inconsistent findings are probably founded in the difference of the sample concerning the severity of burns (mean burn size of 50% versus mean burn size of 8.7%).

Research literature on behavioral problems in preschool children with severe illnesses is scarce. One prospective longitudinal study assessed behavioral problems in children hospitalized as newborns with a critical illness at several time-points up until the age of 12 years. At the age of three years, children in the high-risk medical group had significantly more sleep problems than those in the low-risk medical group and controls. Externalizing problem behavior scores were elevated in 3-year old children in the high-risk medical group, but this difference versus other groups failed to achieve statistical significance (Rautava, Lehtonen, Helenius, & Sillanpää, 2009). A study on psychosocial outcomes among preschool children after heart surgery revealed internalizing behaviors within the normal range, but 13% of the sample exceeded clinical thresholds on the externalizing and total problem scales (Brosig, Mussatto, Kuhn, & Tweddell, 2007).

1.3 Pathogenetic Models of Posttraumatic Stress in Children

A variety of risk and protective factors have been mentioned to influence the development and course of psychological responses to paediatric injuries, illnesses and medical treatment. A blatant deficit in the development of pathogenetic models within the field of childhood psychotraumatology results in the psychological adjustment of children to stressful or traumatic experiences hardly being explained at all via theoretical frameworks (Landolt, 2012). Theoretical models of childhood psychopathology are not only important to study adjustment processes, but also to develop and evaluate intervention strategies. This chapter briefly summarizes a few existing conceptually-based models that aim to predict the adjustment of children to paediatric injuries and illnesses.

1.3.1 Disability-Stress-Coping Model (Wallander & Varni, 1992)

The disability-stress-coping model was developed as a generic theoretical framework to predict children's psychological adjustment to chronic illness, in general. It is based on previous theories of adjustment (Pless & Pinkerton, 1975), family functioning (Moos & Schaefer, 1984) and appraisal and coping (Lazarus & Folkman, 1984). Risk factors potentially contributing to psychological maladjustment are derived from three categories: 1) disease and disability characteristics, such as the diagnosis, level of physical impairment, and visibility of disease; 2) functional dependence in daily activities and living; and 3) psychosocial stressors like critical life events or daily hassles. Protective factors encompass 1)

individual characteristics such as problem-solving abilities, temperament and motivation; 2) family resources and social support; and 3) stress processing abilities, like appraisal and coping strategies. The model postulates a decreased vulnerability to psychological maladjustment when a child displays an adequate number of protective factors (Wallander & Varni, 1992).

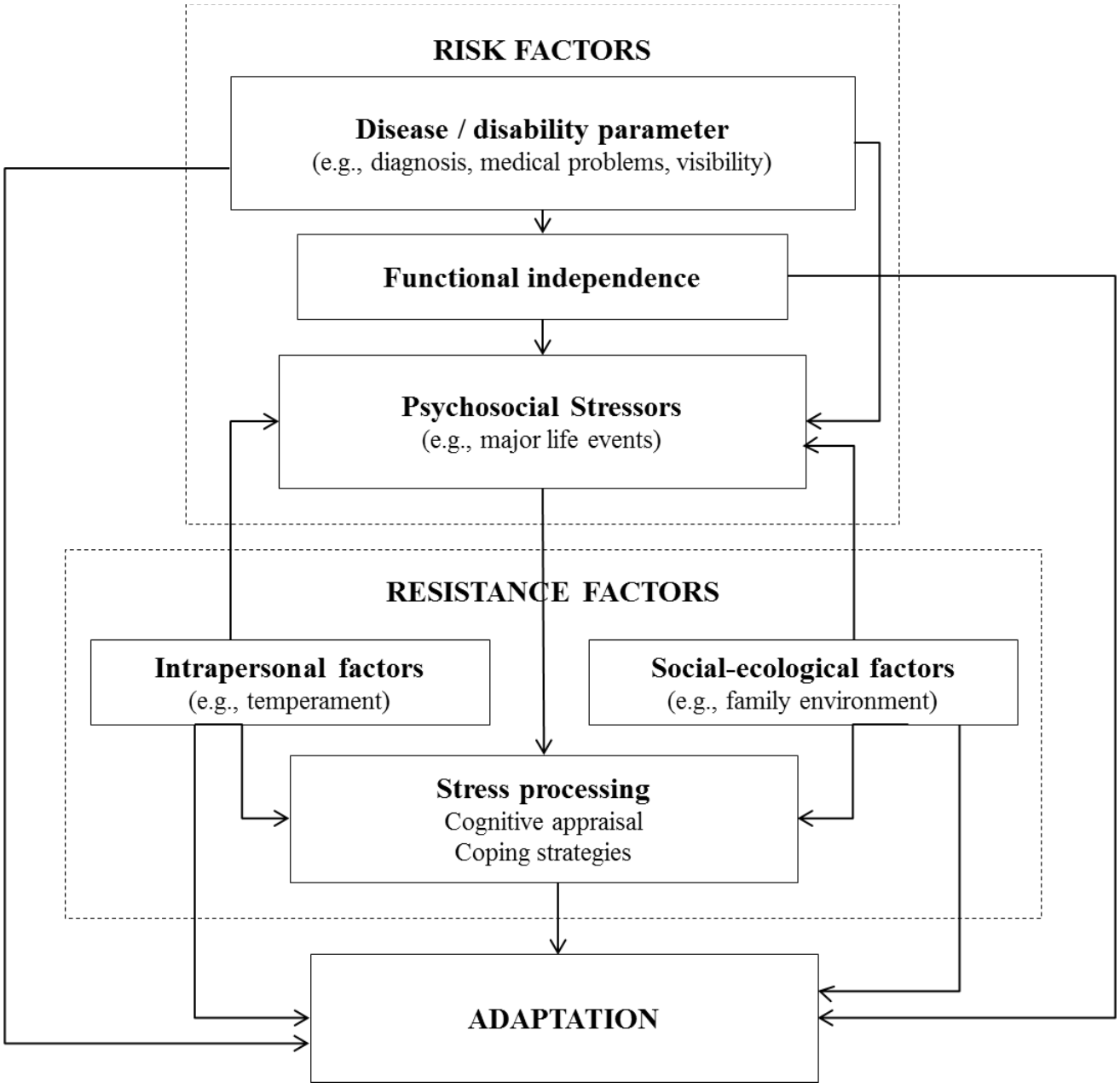

Figure 3 Disability-Stress-Coping Model (Wallander & Varni, 1992)

1.3.2 Transactional Model of Trauma Adaptation (Landolt, 2003)

The transactional model of trauma adaptation also is rooted in the transactional stress theory of Lazarus and Folkman (1984) and integrates current research findings. Posttraumatic adaptation is assumed to be predicted by characteristics of the trauma, the child and the social environment. Characteristics of the trauma include objective, descriptive variables such as the type, duration and severity of the trauma. Characteristics of the child include a wide range of variables, like age, developmental status, gender, temperament, intelligence, pre-traumatic psychopathology and so forth. Characteristics of the environment comprise all social systems relevant for relationships, like family, peers and school, among others. All these determinants may function either as risk or as protective factors. Furthermore, their effect may be direct or indirect; e.g., mediated by appraisal or coping processes. Appraisals and coping processes and the child's adaptation are assumed to mutually interact with each other. Therefore, the same traumatic event can be associated with a large variety of psychosocial responses. Moreover, the transactional model of trauma adaptation is not only valid for posttraumatic stress disorders, but can apply to a variety of posttraumatic reactions (Landolt, 2012).

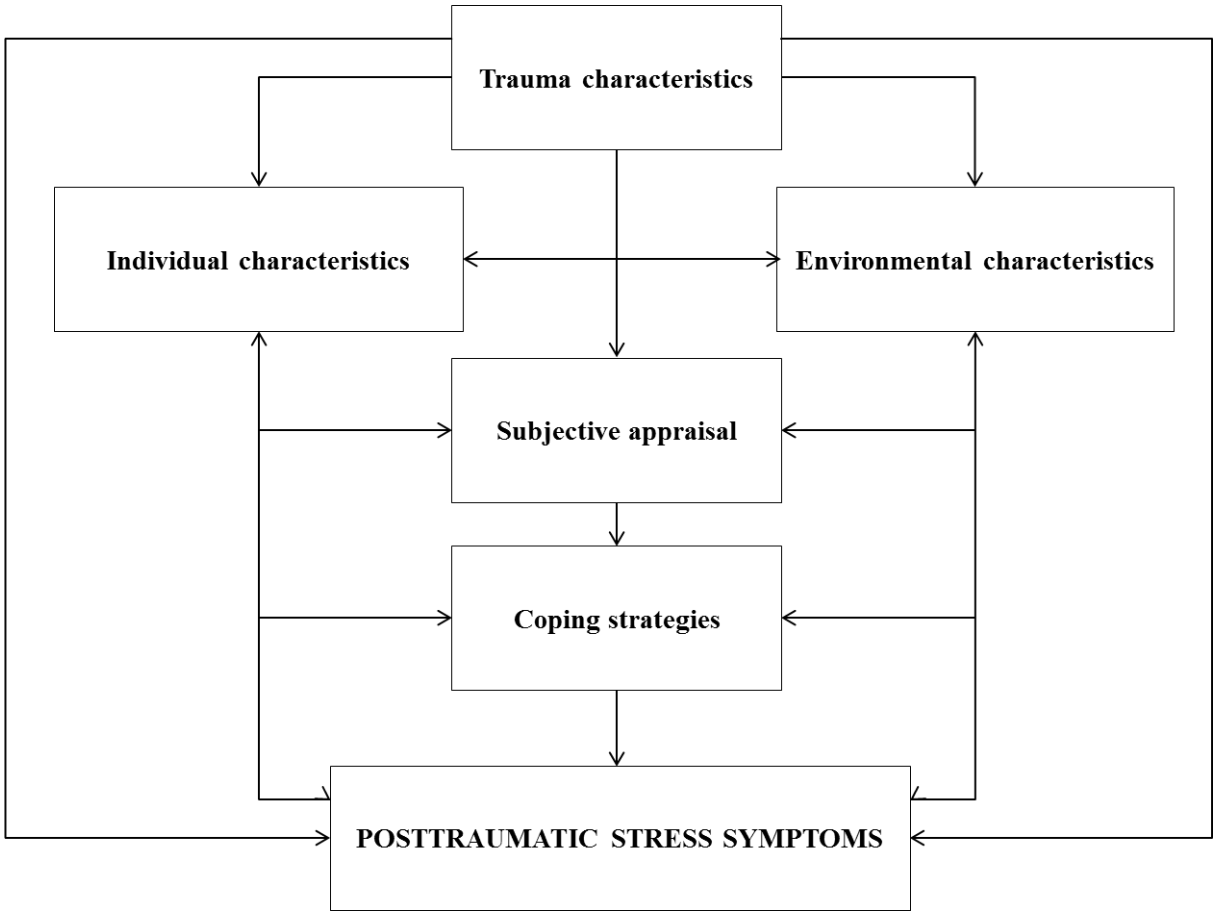

Figure 4 Transactional Model of Trauma Adaptation (Landolt, 2003)

1.3.3 A developmental Psychopathology Model of Childhood Traumatic Stress (Pynoos, Steinberg, & Piacentini, 1999)

In this developmental life-trajectory model, PTSD of children is understood as reaction to the nature of the traumatic experience and to traumatic reminders and so called secondary stressors. The child's acute reaction is assumed to be moderated by (a) proximal trauma reminders (e.g., physiological reactivity); (b) proximal secondary stresses (e.g., changes to family circumstances); (c) the "ecology" of the child (e.g., parental); (d) child intrinsic factors (e.g., genetic predisposition). The child's long-term reaction or adjustment is considered to be influenced by ongoing reminders and persistent secondary stressors (e.g., physical disability) (Pynoos et al., 1999). Pynoos and colleagues suggested that protective and risk factors develop from childhood through adolescence.

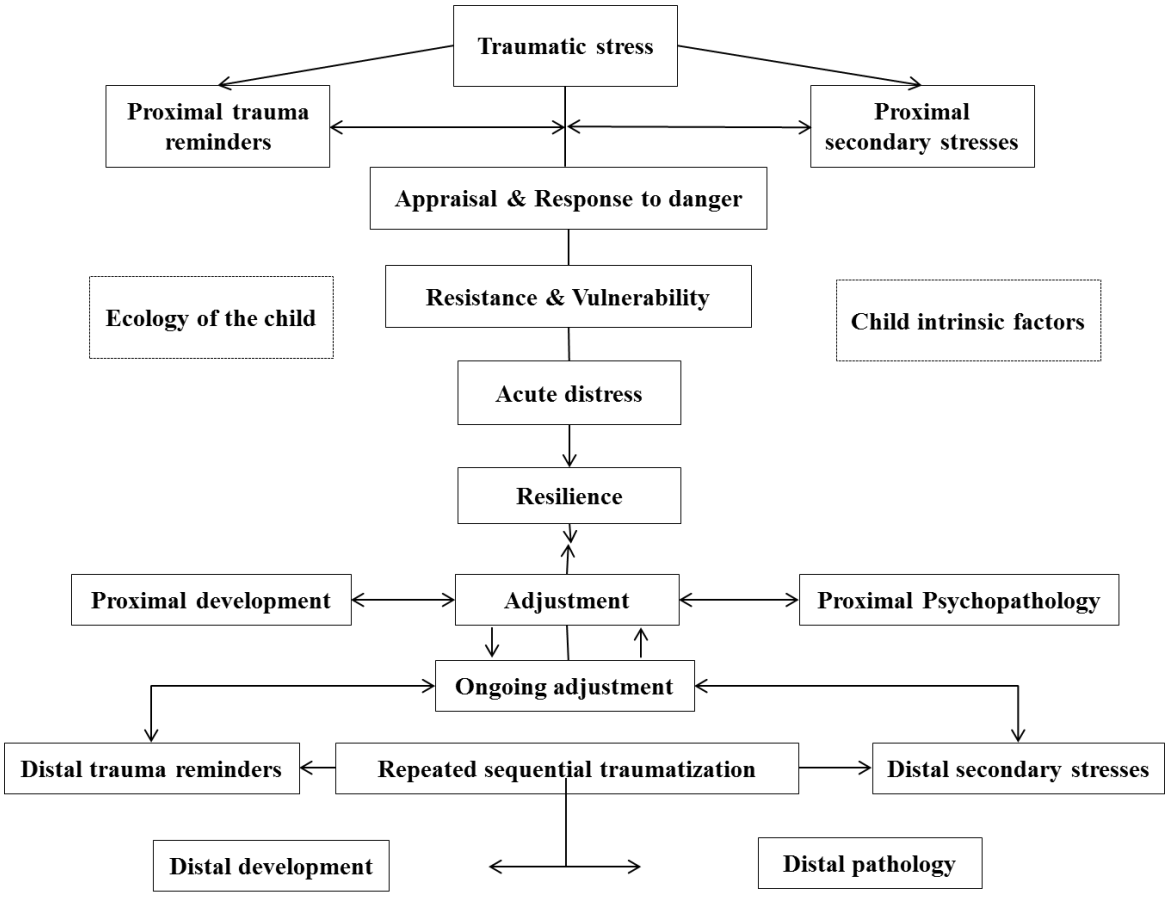

Figure 5 Developmental Psychopathology Model of Childhood Traumatic Stress (Pynoos et al., 1999)

1.3.4 Integrative Model of Paediatric Medical Traumatic Stress (Kazak et al., 2006)

As one of the pioneer research groups in the field of traumatic stress in paediatric cancer patients, Kazak and colleagues integrated clinical and research knowledge into a conceptual model of paediatric medical traumatic stress (PMTS) in order to guide assessment and intervention strategies. Paediatric medical traumatic stress refers to « a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences » (The National Child Traumatic Stress Network, 2004). PMTS includes acute and posttraumatic stress, and is measured by means of a cluster of PTSD symptoms associated with medical events, rather than by diagnosis (Kazak, Schneider, & Kassam-Adams, 2009). The model proposes three phases of traumatic stress response to illness and injury. Phase 1, or the peri-traumatic phase, represents that segment of time during and immediately following the potentially-traumatic medical event. The model emphasizes the determining role of pre-existing factors, subjective appraisal and characteristics of the event, whether a medical event is perceived as traumatic or not. Early responses and physiological arousal have been shown to be predictive of the course of PMTS (Kazak et al., 2009). Phase 2 stands for the early, ongoing and evolving response which usually develops with the physical consequences of injury, illness and treatment, such as pain, repeated admissions to the hospital, having to endure invasive medical procedures, losing one's hair, and so on. It has been shown that parental anxiety during treatment as well as the child's acute stress symptoms over the first few months are associated with later PTSD (Kazak & Barakat, 1997; Kassam-Adams & Winston, 2004). Finally, Phase 3 refers to long-term responses after initial treatment is concluded (Kazak et al., 2006).

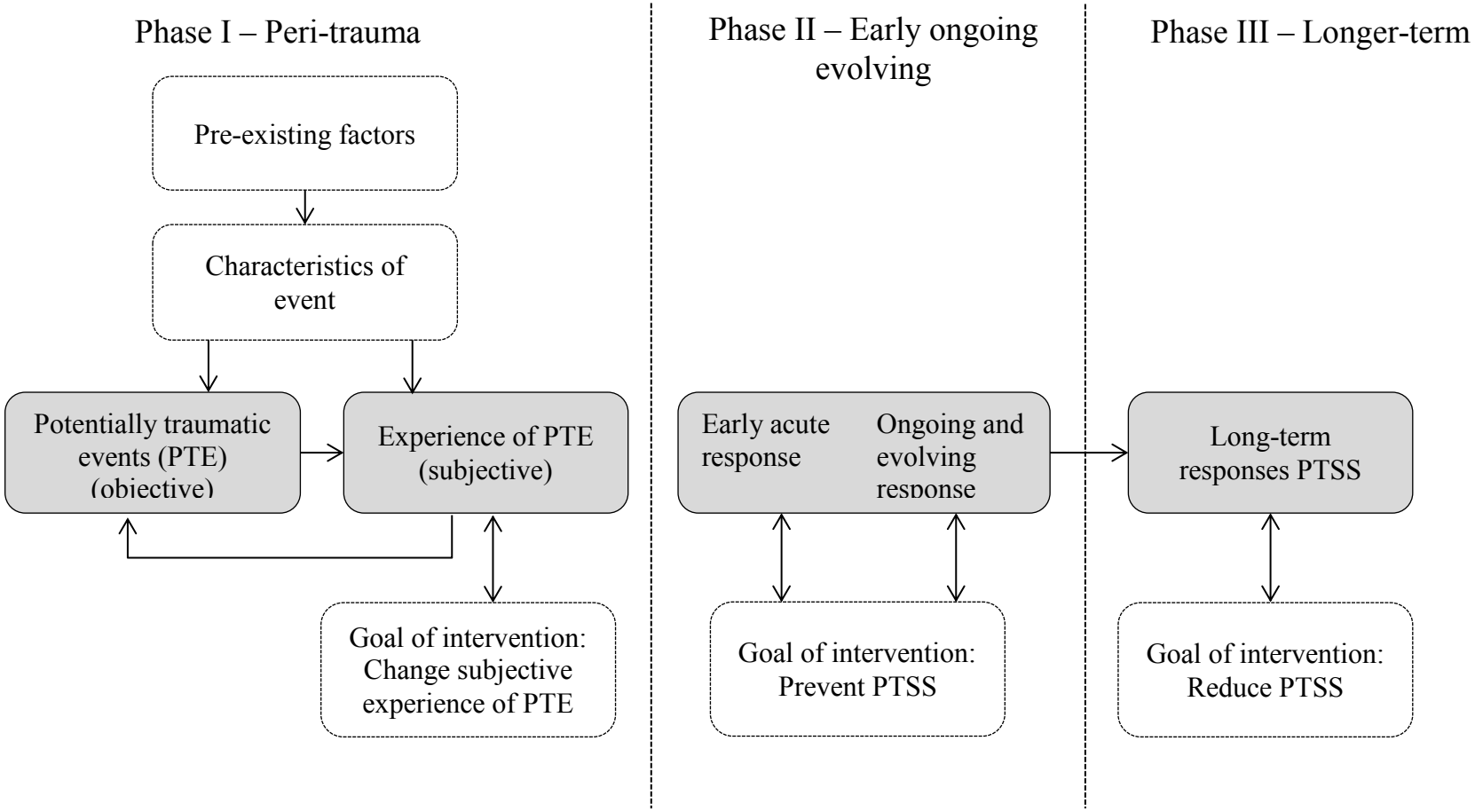

Figure 6 Integrative Model of Paediatric Medical Traumatic Stress (Kazak et al., 2006)

In summary, little theory has been developed to understand childhood PTSD. Existing theories largely are based on adult trauma theory and mostly provide an overview of general risk factors. However, the overarching model of these general risk and protective factors was confirmed in a recent meta-analysis (Alisic, Jongmans, Van Wesel, & Kleber, 2011). There are some efforts to adjust and test more specific theories of trauma pathogenesis in childhood such as the relational PTSD model (Scheeringa & Zeanah, 2001) proposing a compound and mutual effect of child's PTSD symptoms and parent's distress and reduced responsiveness (Bruce, 2006). However, a developmental perspective has only been integrated in the model of Pynoos and colleagues. Nonetheless, the model's basic assumptions also are rooted in the transactional stress theory (Lazarus & Folkman, 1984) developed for adults.

Considering the developmental differences in presentation of PTSD symptoms, a different pathogenesis compared to older children and adults is supposable. For example, young children possibly don't perceive the life-threat of a medical condition, but rather fear specific aspects of medical procedures or suffer from temporary separation of parents. Young children might encode and resolve traumatic experiences differently (Salmon & Bryant, 2002). Encoding of traumatic events, appraisal and representation in memory are information processing sequences that are influenced by the child's knowledge base and language development. Similarly, language and prior knowledge are factors also relevant for resolving the traumatic experiences. The capacity to regulate emotions, to recall information from memory, and to engage in conversation with adults are further developmental factors affecting the posttrauma adjustment (Salmon & Bryant, 2002). However, the recognition of developmental issues in pathogenetic models of posttraumatic stress remains outstanding, and would be of value for generating testable hypotheses as well as for directing treatment strategies (Alisic et al., 2011).

1.4 Conclusions

As outlined in this section, infants and preschoolers are at relatively high risk of exposure to severe paediatric injuries and illnesses, such as burns or cancer. Although severe injuries and illnesses have been acknowledged to be potentially traumatizing, very few studies have included preschool children; and, up to the date of this doctoral thesis, no study has assessed

long-term PTSD in young children with burns or cancer[1]. Due to the long-held notion that young children lack the developmental capacities to experience psychopathology, and the challenge of assessing mental health in this age group, infants and preschoolers have largely been neglected. Coincident with recognizing the importance of early mental health and the development of age-appropriate diagnostic assessment measures, systematic research has now increased. However, the literature on preschool-age children still lags significantly behind that on school-age children. The theoretical background from which hypotheses about influencing factors can be generated remains fragmented, and developmental issues have hardly been included in theoretical models of childhood trauma adaptation. Prior to initiation of this PhD-project, only one longitudinal study looked at predictors of PTSD in preschool children (Laor et al., 1997). Furthermore, despite the evidence-supported association between parent-child relationships and PTSD, to date, fathers have not been included in studies on preschool children. Prior to the current project, only a few studies assessed PTSD via developmentally-sensitive diagnostic interviews, and most of these studies were conducted by the same research group of Scheeringa et al.

In conclusion, infants and preschoolers are an important component of the paediatric population and deserve much-needed attention. Further research on the prevalence of PTSD and its determinants is warranted, to aid in understanding and sufficiently addressing the mental health needs of injured and severely ill infants and preschoolers. Despite the challenge of empirical and clinical work within this age group, there is the potential to improve mental health and minimize the impact of medical trauma on children's ongoing development.

1.5 Study at University Children's Hospital Zurich

In this chapter, the thesis is outlined, objectives and research hypothesis are presented, and the methodology of the research project and measures utilized are introduced.

This thesis is based on a broader study on psychological adjustment of infants and pre-schoolers after burn injuries and cancer diagnosis. The study was initiated by Prof. Markus A.

[1]The recent study of De Young et al. (2012) only was released after publication of our results on children with burns.

Landolt (Department of Psychiatry and Psychosomatics) and conducted at University Children's Hospital in Zurich between 2006 and 2010. The author of the present doctoral thesis was employed as a research fellow. Under the supervision of Prof. Markus A. Landolt, she made significant contributions to the study design and was responsible for the composition of the interview and questionnaires for parents and physicians, the recruitment of families, the acquisition of data, statistical analyses, and the composition of the three journal articles mainly constituting this doctoral thesis.

The study was financially supported by the Claus Cramer Foundation, the Hermann Klaus Foundation, and Oncosuisse.

1.5.1 Objectives and Hypothesis

The general aim of the study was to investigate a broad range of psychological adjustments, including posttraumatic stress symptoms and behavioral changes in infants and preschoolers with burns injuries or cancer. Furthermore, following the above-outlined transactional model of trauma adaptation (Landolt, 2003), the study aimed to identify individual, medical and family risk factors contributing to psychological maladjustment in injured and severely ill infants and preschoolers (Figure 7). As an overlying goal, the study was designed to sensitize and support professionals in their clinical work with very young paediatric patients and their families by enhancing understanding through increased empirical knowledge.

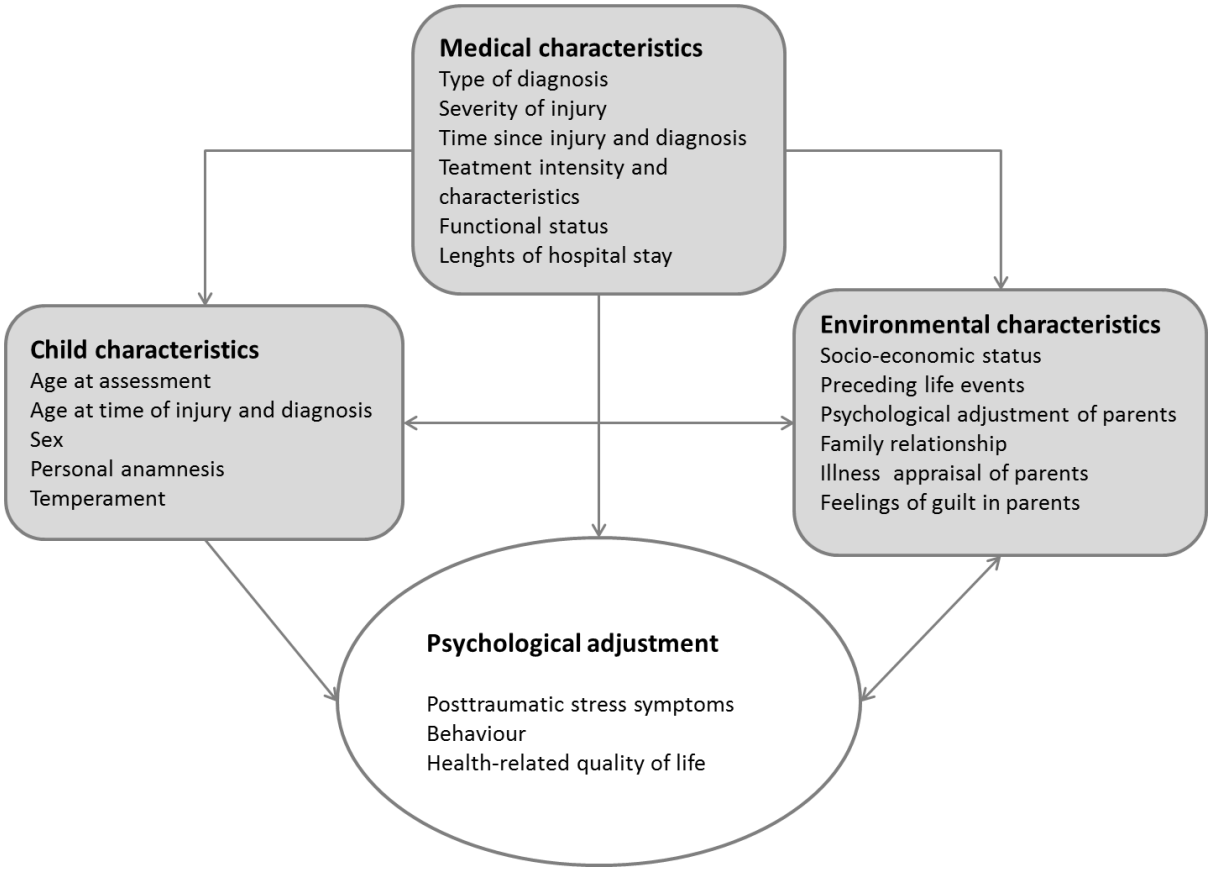

Figure 7 Schematic diagram of the predictors of child's psychological adjustment (adapted from (Landolt, 2003))

The following research questions and hypothesis formed the basis of the investigations:

1) Research question: Do infants and preschoolers develop posttraumatic stress symptoms and behavioral problems when being treated for burn injuries or cancer?
   Hypothesis 1: PTSD prevalence rates in infants and preschoolers with burn injuries or cancer are comparable to rates in older children with the same conditions.
   Hypothesis 2: Levels of behavioral problems are not elevated in burn-injured and severely ill infants and preschoolers, relative to healthy children.
2) Research question: Which individual, medical and family factors influence PTSD and behavioral problems after burn injuries or cancer in infants and preschoolers?
   Hypothesis 1: Following the few preliminary studies on acute stress in burned preschoolers, we expected medical variables to influence the development of PTSD.

Hypothese 2: Given the great dependence and reliance of young children upon their primary caregivers, we expected parental PTSD to be associated with the development of PTSD.

1.5.2 Methods

The initial overview on PTSD in early childhood emphasized specific developmental issues and associated challenges while assessing PTSD in infants and preschoolers. The results of this review determined the focus of the two subsequent cross-sectional investigations, applying a semi-structured interview and questionnaires to collect data.

Participants and Procedures

Young children with burn injuries and cancer were eligible for the study if the following criteria were met: (a) hospitalization at the University Children's Hospital Zurich; (b) at least 3 months since burn incident or cancer diagnosis; (c) no previous evidence of mental retardation; and (d) German speaking parents. After the study was approved by the institutional review board, parents of eligible children were invited consecutively by letter to participate in the study over a period of three years. In the absence of any response, families were contacted by phone, reminded of the study letter and, in cases in which participation was refused, politely asked for reasons and certain demographic characteristics. When informed consent was provided, families were contacted by phone in order to schedule an interview appointment. Semi-structured interviews were conducted with the child's mother at the family home at least three months after either the burn incident or cancer diagnosis. Additionally, both parents were given questionnaires and asked to return them within two weeks of the interview. In the sample of paediatric cancer patients, attending physicians were asked to complete questionnaires on medical data within two weeks of the maternal interview. Medical data on the burn-injured sample were retrieved from hospital records.

The final sample consisted of 154 children (response rate 84%) aged 8 to 49 months. Average time lapse post-burn was 14.8 months respectively 15.6 months since diagnosis.

Measures

The maternal interview and questionnaires for parents and physicians were comprised of standardized measures, as well as self-developed questions and scales.

Child PTSD symptoms were assessed using the German version (Irblich, Hepton, & Landolt, 2006) of the *Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children* (PTSDSSI) (Scheeringa & Zeanah, 2005b). The PTSDSSI is an examiner-based interview that is conducted with the child's primary caregiver and can be used in children from 9 months to 6 years. Responses of caregivers reflect the frequency with which each PTSD symptom is observed on a 3-point Likert scale. When endorsed, examples must be provided. Follow-up questions and clarifications are used until the interviewer is persuaded that the symptom is present and as severe as indicated. The PTSDSSI includes all the empirically-validated developmental modifications and allows for diagnosis either according to the DSM-IV algorithm or to the PTSD-AA for infants and preschoolers. The latter does not require criterion A2 (the child's reaction at the time of the event). Only one instead of three symptoms is required to meet cluster C (symptoms of avoidance and emotional numbing) and two symptoms are required to meet cluster D (symptoms of hyperarousal). Symptoms must have been present for at least one month (criterion F) and cause impairment in at least one significant life area (criterion F). Good inter-rater reliability and validity of this measure have been confirmed in several studies (Scheeringa et al., 2001; Scheeringa et al., 2003; Scheeringa, Zeanah, Myers, & Putnam, 2005).

The *maternal questionnaire* assessed domains concerning the child, the mother herself, and the family. The questionnaire contained biographic information about the child (e.g., complications during pregnancy and birth), questions on maternal appraisal of injury and questions on maternal education and occupation. **Appraisal of illness and treatment** was assessed with a scale that has been validated previously in paediatric patients (Vollrath, Landolt, & Ribi, 2004). Parents were asked to answer questions regarding seven parameters (threat, curability, controllability, visibility, distress, vulnerability, and hope). All except the parameters controllability and distress referred to the child's condition. The answer format was a three-point Likert scale (1–3) with different verbal descriptors for each level. **Child's preexisting temperament** was assessed via the German short version (Saile, 1987) of the *Toddler Temperament Scale (TTS)* (Fullard, McDevitt, & Carey, 1984). Mothers rated each of 50 items on a 5-point Likert scale. Items can be allocated into 6 temperament categories: interference; reaction to new situations (approach vs. withdrawal); urge to be active; attentiveness; prevailing mood; and sensitivity in reactions to bodily sensation. **Behavioral problems** were assessed with the *Child Behavior Checklist 1½-5* (CBCL/1½-5)

(Achenbach & Rescorla, 2000), a 100-item standardized parent-report measure of behavior and emotional problems in children. Higher scores indicate a greater number and intensity of problems. In these studies the German version was used (Arbeitsgruppe Deutsche Child Behavior Checklist, 2002), and only parents of children older than age 18 months were asked to fill in the questionnaire. Reference T-scored values are provided by a community sample of 700 healthy U.S. children age 18 to 71 months. The CBCL was previously shown to have excellent reliability and validity (Achenbach & Rescorla, 2000).

Child's health-related quality of life (HRQOL) was assessed with the *Netherlands Organization for Applied Scientific Research Academic Medical Centre (TNO-AZL) Preschool children Quality of Life (TAPQOL)* (Fekkes et al., 2000). The TAPQOL was designed to assess HRQOL of children with chronic diseases between the ages of 1 and 5 years. The TAPQOL is a 43-item questionnaire consisting of 12 scales that cover the following domains: physical (stomach, skin, lungs, sleep, appetite, motor functioning), cognitive (communication), social (social functioning, problem behaviors), and emotional functioning (anxiety, positive mood, liveliness). The questionnaire asks about issues in any of the above-mentioned areas. If reported, the child's emotional response to the problem was assessed. Higher scores indicate better HRQOL.

Maternal trauma history and posttraumatic stress symptoms were assessed with the *Posttraumatic Diagnostic Scale* (PDS) (Foa, Cashman, Jaycox, & Perry, 1997). The scale is widely used for screening and assessing PTSD in clinical and research settings. These studies used the German version of the PDS (Steil & Ehlers, 2000), which demonstrated excellent psychometric properties. **Maternal psychiatric symptoms** were measured with the *Symptom-Checklist-27 (SCL-27)* (Hardt & Gerbershagen, 2001), a self-report questionnaire containing six symptom subscales; depressive, dysthymic, vegetative, agoraphobic, sociophobic symptoms, and symptoms of mistrust, as well as a global symptom severity index. The occurrence of 12 **preceding life events** such as divorce, unemployment, or severe illness in the family was assessed from mothers for the 12 months preceding the burn incident or cancer diagnosis (Landolt & Vollrath, 1998). A life event score for each family was computed by counting the number of life events reported. Finally, the **quality of family relationships** was assessed using the German version (Schneewind, Beckmann, & Hecht-Jackl, 1985) of the *Family Relationship Index* (FRI) (Moos & Moos, 1994). This 27-item questionnaire consists of three subscales of the Family Environment Scale assessing cohesion, expressiveness, and conflict. Each scale is composed of nine items that traditionally are scored using a true-false

format (0 or 1). For the purposes of our study, we extended the answer scale to a 3-point Likert scale consisting of the response options not true (0), partially true (1), and true (2).

The *fathers' questionnaire* covered the following domains concerning the child and the father himself and used the same questionnaires as described above: 1) paternal appraisal of injury, illness and treatment; 2) the child's health-related quality of life; 3) trauma history and paternal posttraumatic stress symptoms; 4) paternal psychiatric symptoms; and 5) questions on education and occupation. The **socioeconomic status** (SES) of the family was calculated by means of a 6-point scale of both paternal occupation and maternal education (range 2-12). Three socioeconomic classes were defined as follows: scores 2-5 as lower SES; scores 6-8 as middle SES; scores 9-12 as upper SES.

The *physician's questionnaire* consisted of questions regarding the cancer diagnosis, the intensity and kind(s) of treatment, length of hospitalization, medical complications, compliance, treatment impact on daily functioning, and functional status of the child. Table 2 summarizes all the measures used in the questionnaires.

Table 2 Measures of the studies

Data source	Instruments
Interview with mother	• Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children (PTSDSSI) (Scheeringa & Zeanah, 2005b)
Parent questionnaire	• Biographic information about child* • Information about the burn accident, subjective appraisal of burn treatment and rehabilitation (self-developed questions)*/** • Number of side effects through cancer treatment (self-developed question)* • Illness appraisal of child and parents (Vollrath et al., 2004)** • Toddler Temperament Scale (TTS) (Fullard et al., 1984)*/** • Child Behavior Checklist 1½-5 (CBCL 1½-5) (Achenbach & Rescorla, 2000)* • The Netherlands Organization for Applied Scientific Research Academic Medical Centre (TNO-AZL) Preschool children Quality of Life (TAPQOL) (Fekkes et al., 2000)** • Life events in the family * (Landolt & Vollrath, 1998) • Posttraumatic Diagnostic Scale (PDS) (Foa et al., 1997) • Symptom-Checklist-27 (SCL-27) (Hardt & Gerbershagen, 2001)** • Family Relationship Index (FRI) (Schneewind et al., 1985; Moos & Moos, 1994)*
Physicians' questionnaire	• Medical information: Type of cancer, treatment phase, date of diagnosis, type of treatment, intensity of treatment, medical complications, compliance, treatment impact on daily functioning, current functional status
Hospital records	• Number of dressing changes under anesthesia • Cumulative days of hospitalization

* Only in mothers' questionnaire

** Not included in final data analysis

2

Posttraumatische Belastungsstörungen bei Säuglingen und Kleinkindern

Graf, A., Irblich, D., & Landolt, M.A. (2008). Posttraumatische Belastungsstörungen bei Säuglingen und Kleinkindern. *Praxis der Kinderpsychologie und Kinderpsychiatrie, 57,* 247-263.

Summary

Posttraumatic stress disorder in infants and toddlers

While the occurrence of posttraumatic stress disorders (PTSD) in children and adolescents is undoubted, knowledge about the disorder in infants and toddlers is scarce. The lack of an accurate research base is mainly due to challenges in assessing PTSD in infants and toddlers. The development of an alternative set of diagnostic criteria, its empirical testing and the design of an examiner-based interview are recent and important steps. This article reviews the literature on PTSD in infants and toddlers. It defines the disorder and emphasizes its distinctive features in this age group. Demonstrating the development of an alternative set of diagnostic criteria and overviewing the existing assessment tools are central issues. A German version of the *Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children (Scheeringa & Zeanah, 2005b)* is presented for the first time. The state of research in prevalence and therapy of PTSD in infants and toddlers is described and recommendations for research and clinical practice are provided.

Zusammenfassung

Während das Auftreten posttraumatischer Belastungsstörungen (PTBS) bei Kindern im Schulalter und bei Jugendlichen heute als unbestritten gilt, ist das entsprechende Wissen in Bezug auf Säuglinge und Kleinkinder viel geringer. Mit der Entwicklung von alternativen Diagnosekriterien, deren empirischer Überprüfung und Abbildung in einem klinischen Interview wurden erste wichtige Schritte zu deren Erfassung unternommen. Die vorliegende Arbeit definiert PTBS und hebt Besonderheiten für das Säuglings- und Kleinkindesalter hervor. Die Entwicklung der alternativen Diagnosekriterien (AK) sowie eine Übersicht zu Möglichkeiten der systematischen Erhebung von PTBS im Säuglings- und Kleinkindesalter stehen im Zentrum. Dabei wird das Erhebungsinstrument *Posttraumatische Belastungsstörung - Semistrukturiertes Interview und Beobachtungsbogen für Säuglinge und Kleinkinder (PTSDSSI) (Scheeringa & Zeanah, 2005b)* erstmals in einer deutschsprachiger Version vorgestellt. Der aktuelle Forschungsstand im Bereich der Prävalenz von PTBS sowie psychotherapeutischer Interventionen im Säuglings- und Kleinkindesalter wird dargelegt. Den Abschluss bilden Empfehlungen für Forschung und Praxis.

2.1 Einleitung

Verglichen mit dem Kenntnisstand zu Traumafolgestörungen bei Kindern ab dem Schulalter, gibt es für das Säuglings- und Kleinkindesalter nur ganz vereinzelte Studien zur Prävalenz posttraumatischer Belastungsstörungen (PTBS) nach spezifischen Psychotraumata. Dies erstaunt, wenn man um die Bedeutung der ersten Lebensjahre als einem besonders vulnerablen Lebensabschnitt weiss (Petermann, Niebank, & Scheithauer, 2000). Die Schwierigkeiten liegen in der Erhebung posttraumatischer Symptome in dieser Altersspanne. Eingeschränkte kognitive und sprachliche Fertigkeiten stehen einer systematischen Erfassung von PTBS im Säuglings- und Kleinkindesalter entgegen. Seit Mitte der 1990er Jahre gibt es jedoch vertiefte Versuche, die Validität der Diagnosekriterien einer PTBS auch bei Säuglingen und Kleinkindern zu überprüfen (Scheeringa et al., 1995; Scheeringa et al., 2001; Scheeringa et al., 2003, 2005). Untersuchungen bestätigen, dass PTBS als spezifische Stressreaktion auch bei Säuglingen und Kleinkindern vorkommen kann. Die herkömmlichen Diagnosekriterien sind in dieser Altersgruppe jedoch nicht sensitiv genug, was zur Entwicklung von alternativen Kriterien (AK) mit deutlich verbesserter Validität für das Säuglings- und Kleinkindesalter führte.

Im Folgenden wird ein Überblick über die Literatur zum Thema PTBS bei Säuglingen und Kleinkindern unter besonderer Berücksichtigung von diagnostischen und therapeutischen Aspekten gegeben. Erstmals wird dabei in autorisierter deutscher Version das von Scheeringa and Zeanah (2005b) entwickelte semistrukturierte Interview zur Erfassung der PTBS im Säuglings- und Kleinkindalter vorgestellt.

2.2 Die posttraumatische Belastungsstörung

2.2.1 Herkömmliche Diagnosekriterien

Die Definition eines Traumas gemäss DSM-IV-TR (Sass, Wittchen, Zaudig, & Houben, 2003) beinhaltet zwei Aspekte, die gleichzeitig erfüllt sein müssen:

(A1) Das betroffene Individuum erlebt oder beobachtet ein Ereignis, welches mit einer ernsthaften Bedrohung der körperlichen oder psychischen Integrität der eigenen Person oder anderer Personen einhergeht.

(A2) Die unmittelbare Reaktion des betroffenen Individuums beinhaltet intensive Furcht, Hilflosigkeit, Grauen, aufgelöstes oder agitiertes Verhalten.

Die dadurch ausgelösten Symptome werden drei Bereichen zugeordnet: (B) Wiedererleben, (C) Vermeidung und Abflachung der allgemeinen Reagibilität, (D) Übererregung.

Die Diagnose einer PTBS wird gemäss DSM-IV gestellt, wenn eine bestimmte Anzahl von Symptomen aus den Bereichen B bis D mindestens einen Monat lang andauert und klinisch signifikante Beeinträchtigungen im Alltag zur Folge haben.

2.2.2 Alternative Diagnosekriterien für Säuglinge und Kleinkinder

Die heute gängigen Diagnosekriterien erfassen die Symptommanifestationen einer PTBS vorwiegend durch Introspektion und verbale Beschreibung innerer Zustände durch die Betroffenen selbst. Obwohl entwicklungsbedingte Voraussetzungen zur Ausbildung einer PTBS bereits ab dem Alter von neun Monaten vorhanden sind (Drell, Siegel, & Gaensbauer, 1993), fehlen bei den meisten Kindern unter drei Jahren die kognitiven und sprachlichen Möglichkeiten zur Introspektion und dem verbalen Beschreiben innerer Zustände (Scheeringa, 2004). Es ist anzunehmen, dass sich diese Tatsache auf die klinische Manifestation der Symptomatik und insbesondere auf ihre Erfassung im Säuglings- und Kleinkindesalter auswirkt. Entsprechend kann das Vorliegen einer PTBS bei Kindern im Vorschulalter nicht mittels der herkömmlichen, bei Erwachsenen entwickelten DSM-Kriterien erfolgen, sondern es bedarf altersangepasster Kriterien (Scheeringa et al., 2003).

Die Entwicklung solcher altersangepasster Kriterien (vgl. Tab. 3) und deren Abbildung im Erhebungsinstrument *Posttraumatische Belastungsstörung - Semistrukturiertes Interview und Beobachtungsbogen für Säuglinge und Kleinkinder (PTSDSSI) (Scheeringa & Zeanah, 2005b)* folgte aus einer Reihe von Untersuchungen. Ausgangspunkt für die erste systematische Studie auf dem Gebiet der PTBS bei Säuglingen und Kleinkindern war die Feststellung, dass bei 20 publizierten Falldarstellungen schwer traumatisierter Kinder zwar zahlreiche PTBS-Symptome beschrieben worden waren, keines der Kinder aber die DSM-IV-Kriterien für die Diagnose einer PTBS vollständig erfüllte (Scheeringa et al., 1995). Als Ursache machten die Autoren zu grosse Sprachgebundenheit, unzureichende Alterssensitivität und eine zu hohe Zahl erforderlicher Symptome pro Cluster aus. Ausserdem bestand für etliche Items eine niedrige Beurteilerübereinstimmung.

Tabelle 3 Alternative Diagnosekriterien für PTBS im Säuglings- und Kleinkindesalter (Scheeringa et al., 2003)

Symptomgruppen	**Symptome**
A. Traumatisches Ereignis	
B. Wiedererleben ► mindestens 1 Symptom	• Posttraumatisches Spiel: Zwanghafte Wiederholung von Themen und Aspekten des Traumas, kein Angstabbau durch das Spiel. Weniger elaboriertes und kreatives Spiel • Nachspielen bestimmter Aspekte des Traumas, ohne Charakteristika des posttraumatischen Spiels • Wiederholte Erinnerung des traumatischen Ereignisses ausserhalb des Spiels, ohne offensichtliche psychische Belastung • Albträume mit Bezug zum Trauma oder mit zunehmender Frequenz ohne wieder erkennbaren Inhalt • Episoden mit objektiven Anzeichen eines Flashbacks oder von Dissoziation • Psychische Belastung bei der Konfrontation mit Hinweisreizen
C. Vermeidung ► mindestens 1 Symptom	• Tatsächliche oder versuchte Vermeidung von Aktivitäten, Gegenständen, Orten oder Personen, welche mit dem Trauma assoziiert sind • Einengung des Spielverhaltens • Sozialer Rückzug • Eingeschränkte Bandbreites des Affekts
D. Erhöhte Erregung ► mindestens 2 Symptome	• Ein- und Durchschlafschwierigkeiten • Erhöhte Irritierbarkeit, Wutausbrüche, Affektlabilität • Verringerte Konzentrationsfähigkeit im Vergleich zu vor dem Trauma • Übertriebene Wachsamkeit (Hypervigilanz) • Übertriebene Schreckreaktion
E. Neue Ängste und Aggressionen ► für die Diagnose nicht erforderlich	• Verlust bereits erworbener Fertigkeiten insbesondere im Bereich der Sauberkeitsentwicklung und der Sprache • Neu auftretende Ängste • Neu auftretende Trennungsangst • Neu auftretende Aggressionen

In der Folge entwickelten die Autoren eine erste Version von AK für das Säuglings- und Kleinkindesalter. Ausgangspunkt bildeten die herkömmlichen Kriterien nach DSM-IV sowie die in der Literatur beschriebenen Symptome schwer traumatisierter Säuglinge und Kleinkinder. Symptome, die nicht direkt über die Beobachtung des kindlichen Verhaltens erfasst werden konnten oder die in dieser Altersspanne schwer zu beurteilen waren, wurden

weggelassen oder neu formuliert. Weitere Änderungen bestanden in der Aufnahme eines entwicklungsspezifischen Symptoms (Verlust bereits erworbener Fertigkeiten) bzw. einer weiteren Symptomgruppe (neu auftretende Aggressionen und Ängste).

Die Anwendung der AK auf 12 neue Fälle traumatisierter Kleinkinder ergab in der Folge eine deutlich verbesserte Entwicklungssensitivität gegenüber den DSM-IV-Kriterien (Scheeringa et al., 1995). Nunmehr wurde in 9 der 12 Fälle eine PTBS-Diagnose gestellt, während auch diesmal nach den DSM-IV-Kriterien von den Beurteilern im Durchschnitt nur 1,5 Fälle als PTBS identifiziert worden wären. Auch in der Beurteilerübereinstimmung ergaben sich bessere Werte für die AK im Vergleich zum DSM-IV. Ergebnisse anderer Forschergruppen bestätigten in der Folge die Handhabbarkeit der AK und führten zu vergleichbaren Prävalenzraten im Bereich von 25-29% für PTBS bei traumatisierten Kleinkindern (Ohmi et al., 2002; Stoddard, Saxe, et al., 2006).

Eine Reihe der genannten Studien beschäftigte sich mit der Frage, wie viele Symptome pro Symptomgruppe jeweils mindestens vorhanden sein müssen (Scheeringa et al., 1995; Scheeringa et al., 2001; Scheeringa et al., 2003; Scheeringa, Wright, et al., 2006). Als optimaler Algorithmus wurde in Abweichung vom DSM-IV das Weglassen der beobachtbaren unmittelbaren Reaktion auf ein traumatisches Ereignis (Cluster A2) sowie die Reduktion der Anzahl Vermeidungssymptome (Cluster C) vorgeschlagen. Hinsichtlich der Symptomgruppe der Übererregung konnte die vorgesehene Reduktion von zwei auf ein erforderliches Symptom empirisch jedoch nicht bestätigt werden. Die zusätzlich eingeführte Symptomgruppe der neu auftretenden Ängste und Aggressionen lieferte keinen entscheidenden Beitrag zu einer verbesserten diagnostischen Validität und wurde daher aus dem Symptomkatalog wieder entfernt, soll aber weiterhin als zusätzliche diagnostische Information mit erhoben werden (Scheeringa et al., 2003).

Nachfolgende Untersuchungen bestätigten die Brauchbarkeit der AK für die PTBS-Diagnose bei Säuglingen und Kleinkindern. In Kontrollgruppendesigns ergaben sich signifikante Häufigkeitsunterschiede zu Vergleichsgruppen (Scheeringa et al., 2003; Scheeringa, Zeanah, Myers, & Putnam, 2004). Zusätzlich konnte die Konstruktvalidität durch theoriekonforme Zusammenhänge mit komorbiden Störungen (Scheeringa et al., 2003) sowie dem Nachweis von typischen psychophysiologischen Korrelaten während der Induktion belastender Erinnerungen bei Kleinkindern mit PTBS bestätigt werden (Scheeringa et al., 2004). Zudem zeigte sich, dass die Stabilität der Traumasymptome und damit die prädiktive Validität der AK über einen Zeitraum von zwei Jahren erstaunlich hoch war (Scheeringa et al., 2005).

2.3 Diagnostische Verfahren bei posttraumatischen Belastungsstörungen im Säuglings- und Kleinkindesalter

Während im Kindes- und Jugendalter die Diagnose einer PTBS möglichst durch ein klinisch-psychologisches Interview mit dem betroffenen Kind sowie im Rahmen eines Gesprächs mit den Eltern erfolgen soll (Landolt, 2004), bestehen für das Säuglings- und Kleinkindesalter diesbezüglich erhebliche Einschränkungen. Kinder unter 6 Jahren sind zu einem validen Selbstbericht über erlebte Symptome meist nicht in der Lage (Scheeringa, Wright, et al., 2006). Standardisierte Beobachtungssituationen, die eine Erfassung von PTBS bei Säuglingen und Kleinkindern vervollständigen könnten, fehlen bis heute gänzlich. Das diagnostische Vorgehen bei PTBS im Säuglings- und Kleinkindesalter hat sich demnach primär an Informationen der primären Bezugspersonen zu orientieren.

Im Gegensatz zum Kindes- und Jugendalter liegt für das Säuglings- und Kleinkindesalter nur eine geringe Anzahl an Erhebungsinstrumenten vor. Zusätzlich zur begrenzten Auswahl sind ausstehende empirische Überprüfungen sowie fehlende Übersetzungen weitere Einschränkungen. Im Folgenden werden neben den in deutscher Sprache verfügbaren Diagnoseverfahren auch weitere Verfahren aus dem angelsächsischen Raum vorgestellt.

2.3.1 Interviewverfahren

PTBS - Semistrukturiertes Interview und Beobachtungsbogen für Säuglinge und Kleinkinder (PTSDSSI): Das PTSDSSI ist ein klinisches Interview, welches mit der primären Bezugsperson von Säuglingen und Kleinkindern durchgeführt werden kann. Ab dem Alter von 9 Monaten erlaubt das Verfahren eine Diagnosestellung, eingesetzt werden kann es jedoch bereits ab einem Alter von wenigen Wochen. Während der Durchführung des Interviews soll sich das Kind im gleichen Raum aufhalten und von der interviewenden Person beobachtet werden. Die nicht standardisierten Beobachtungen können die Aussagen der primären Bezugspersonen ergänzen.

Das PTSDSSI enthält zunächst eine Liste möglicher traumatischer Ereignisse. Die Symptome einer PTBS werden gemäss den AK erfasst. Wird die Präsenz eines Symptoms bestätigt, folgen Fragen zur individuellen Ausprägung, dem situationalen und zeitlichen Auftreten sowie der Dauer. Ausser der Beurteilung der Auswirkungen dieser Symptome auf wichtige Lebensbereiche enthält das PTSDSSI weitere mit diesem Alter assoziierte Begleitsymptome.

Die Diagnosestellung einer PTBS kann entweder nach dem alternativen Algorithmus oder aber nach dem DSM-IV-Algorithmus erfolgen.

Aufgrund der engen Anlehnung des PTSDSSI an die Formulierungen des DSM-IV dürfte die inhaltliche Validität des Verfahrens als gesichert gelten. In mehreren Studien wurde zudem die Konstruktvalidität sowie die prädiktive Validität des PTSDSSI bestätigt (vgl. Kapitel 2.4). In ihrer vergleichenden Bewertung der im angelsächsischen Raum vorhandenen Traumadiagnoseinstrumente für Kinder unter 6 Jahren empfehlen Stover und Berkowitz (Stover & Berkowitz, 2005) das PTSDSSI zudem als einziges der dort dargestellten Verfahren und halten es sowohl für den klinisch-diagnostischen Einsatz als auch für Forschungsvorhaben für geeignet.

Eine erste deutsche Übersetzung des PTSDSSI (Version 1.2) erfolgte 2003 durch Irblich und Hepton unter Mitarbeit von Landolt. Zunehmende Nachfrage von Traumatherapeuten sowie eine Überarbeitung der amerikanischen Version machten 2006 eine vollständige Neuübersetzung des Interviews auf Grundlage der Version 1.4.2005 erforderlich (Irblich et al., 2006)[2]. Dabei wurde auf möglichst grosse Texttreue geachtet und es wurden nach Möglichkeit Formulierungen gewählt, die der deutschen Übersetzung des DSM-IV-TR (Sass et al., 2003) entsprachen. Studien zur Validität und Beobachterübereinstimmung der deutschen Version wurden bislang noch nicht durchgeführt. Neben der deutschen liegt mittlerweile auch eine hebräische Übersetzung vor. Es ist empfehlenswert, bei der Einarbeitung in das Verfahren das englischsprachige Kodierungsmanual[1] zu Rate zu ziehen. Die Befragung und diagnostische Entscheidungsfindung bezüglich Vorliegen oder Ausschluss von Symptomen erfordert, wie bei anderen semistrukturierten Traumadiagnoseinstrumenten auch (vgl. (Irblich & Renner, 2007)), solide traumatherapeutische Kenntnisse. Eine Reihe von Studien belegt die Tendenz, dass insbesondere die Häufigkeit der Symptome des Wiedererlebens von Bezugspersonen häufig unterschätzt wird (Scheeringa, Wright, et al., 2006). Diese Tatsache sollte bei der klinischen Beurteilung unbedingt berücksichtigt werden.

Preschool Age Psychiatric Assessment (PAPA): Neben dem PTSDSSI liegt mit dem PAPA (Egger, Ascher, & Angold, 2002) ein zweites Interviewverfahren vor. Das PAPA ist ein englischsprachiges diagnostisches Instrument für psychische Störungen bei 2-5jährigen Kindern und ermöglicht unter anderem die Diagnose einer PTBS. Das Interview richtet sich an die primären Bezugspersonen der jeweiligen Kinder und liegt in spanischer, rumänischer

[2] Die deutschsprachige Version des PTSDSSI (PTSDSSI-D) sowie die englischsprachige Version des Kodiermanuals können beim korrespondierenden Autor bezogen werden

und norwegischer, nicht jedoch in deutscher Übersetzung vor. Eine erste aktuelle Studie bestätigt die Reliabilität dieses diagnostischen Verfahrens (Egger et al., 2006).

2.3.2 Fragebogenverfahren

In Form eines Eltern-Fragebogens kann die *PTSD Symptoms in Preschool Children (PTSD-PAC)* (Levendosky, Huth-Bocks, Semel, & Shapiro, 2002) bei 3-5jährigen Kindern eingesetzt werden. Die Checkliste basiert auf den DSM-IV-Kriterien und orientiert sich in der Formulierung einzelner Symptome an dem PTSDSSI. Primäre Bezugspersonen werden nach der Präsenz von Symptomen gefragt. Angaben zu Beginn und Häufigkeit der Symptome können jedoch keine gemacht werden. Die psychometrischen Eigenschaften dieses Verfahrens wurden bisher nicht untersucht.

Die *Trauma Symptom Checklist for Young Children (TSCYC)* (Briere, 2005) ist als Eltern-Fragebogen konzipiert und kann bei 3 bis 12jährigen Kindern eingesetzt werden. Die 90 Symptome können in acht übergeordneten klinischen Skalen sowie einer Gesamtskala für posttraumatischen Stress zusammengefasst werden. Letztere erlaubt eine Einschätzung der posttraumatischen Symptomatik, jedoch keine kategoriale Diagnosestellung. Eine Besonderheit dieser Checkliste liegt in zwei Skalen, anhand derer die Validität der Fremdbeurteilung gemessen werden kann. Eine erste Studie belegt für die TSCYC eine zufrieden stellende Reliabilität und Validität (Briere et al., 2001).

Die *Child Behavior Checklist (CBCL)* (Achenbach, 1991) wurde zwar nicht spezifisch für die Erfassung einer PTBS konzipiert, kann jedoch als Screening-Instrument für PTBS eingesetzt werden. Eine für das Säuglings- und Kleinkindesalter modifizierte Skala (Dehon & Scheeringa, 2006) setzt sich aus 15 Symptomen der Version CBCL 1½-5 (Achenbach & Rescorla, 2000) zusammen. Für die PTBS-Skala kann vergleichbar mit den anderen CBCL-Syndromskalen ein Summenscore sowie ein klinischer Grenzwert berechnet werden. Angaben zum kritischen Grenzwert weisen auf eine PTBS-Symptomatik im klinisch relevanten Bereich hin, diese PTBS-Skala erlaubt jedoch keine kategoriale Diagnose. Die psychometrische Eigenschaften der Skala sind zufrieden stellend (Dehon & Scheeringa, 2006).

2.4 Prävalenz posttraumatischer Belastungsstörungen im Säuglings- und Kleinkindesalter

Tabelle 4 zeigt eine chronologische Zusammenstellung von Studien, die die Prävalenz von PTBS im Säuglings- und Kleinkindesalter untersuchten. Mit einer Ausnahme stammen die Untersuchungen aus dem angelsächsischen Raum.

Die bisher einzige verfügbare epidemiologische Studie fand bei 2-5jährigen Kindern gemäss den Diagnosekriterien nach DSM-III und -IV eine Prävalenzrate von 0.1% (Lavigne & Faier-Roumann, 1992). Eine retrospektive Untersuchung an einer amerikanischen psychiatrischen Klinik für Kleinkinder ergab, dass PTBS bei Kindern zwischen 0 und 58 Monaten mit einer Auftretenshäufigkeit von 20% bzw. 21% zu den häufigsten Störungsbildern in dieser Altersgruppe gehört (Frankel, Boyum, & Harmon, 2004). Andere Studien befassten sich mit Säuglingen und Kleinkindern aus Risikopopulationen, z.B. nach Brandverletzungen (Stoddard, Saxe, et al., 2006), technischen Katastrophen (Ohmi et al., 2002), gewalttätigen Ereignissen wie Krieg (Almqvist & Brandell-Forsberg, 1997) oder häuslicher Gewalt (Levendosky et al., 2002) sowie nach gemischten traumatischen Ereignissen (Scheeringa et al., 1995; Scheeringa et al., 2001; Scheeringa et al., 2003, 2005). Die Untersuchungen zeigen, dass bis zu einem Drittel der traumatisierten Kinder die Bedingungen für eine PTBS-Diagnose gemäss den in Tabelle 3 ersichtlichen Kriterien erfüllten. Eine weitere Studie untersuchte langfristige Stressreaktionen nach Brandverletzungen unter Anwendung der deutschsprachigen Version des PTSDSSI sowie den AK und fand bei 15.6% das Vollbild einer PTBS (Graf, Schiestl, & Landolt, 2011). Die bisher einzige verfügbare Längsschnittstudie weist nach, dass die PTBS-Prävalenzrate gemäss AK auch zwei Jahre nach unterschiedlichen traumatischen Ereignissen noch bemerkenswert hoch ist und im Gegensatz zu älteren Kindern nicht abnimmt (Scheeringa et al., 2005).

Tabelle 4 Zusammenstellung von PTBS-Prävalenz-Studien im Säuglings- und Kleinkindesalter

Autoren Jahr	**Alter**	**N**	**Design**	**Art des Traumas**	**Dauer seit Trauma**	**Diagnose-instrument**	**Prävalenzrate**	
Almqvist & Brandell-Forsberg, 1997	(1) 4-8 J. (2) 6-10 J.	50	Prospektiv	Krieg und politische Verfolgung der Eltern	(1) ca. 1J. (2) 3 ½ J.	DSM-III Sandspiel Beobachtung	Nur DSM-III (1) 2% (2) 10%	Alle Methoden (1) 21%: (2) 21%
Frankel et al., 2004	0-58 Mt.	177	Retrospektiv	Gemischt		DSM-IV DC 0-3	DSM-IV 20%	DC 0-3 21%
Graf et al., 2007	19-48 Mt.	45	Retrospektiv	Brandverletzungen	6 Mt. – 48 Mt.	PTSDSSI[1]	AK: 15.6%	
Lavigne et al., 1996	2-5 J.	3860	Retrospektiv Epidemiologisch	Gemischt		CBCL[2] C-GAS[3]	DSM-III / IV: 0.1%	
Levendosky et al., 2002	3-5 J.	62	Retrospektiv	Häusliche Gewalt gegen die Mutter	0 Mt.	PTSD-PAC[4] CBCL[5]	PTSD-PAC 3%	CBCL 24%
Ohmi et al., 2002	32-73 Mt.	32	Prospektiv	Gasexplosion	(1) 10 T. (2) 6 Mt. (3) 1 J.	PTSDSSI	DSM-IV (2) 0%	AK (2) 25%

Autoren Jahr	Alter	N	Design	Art des Traumas	Dauer seit Trauma	Diagnose-instrument	Prävalenzrate	Autoren Jahr
Scheeringa et al., 1995	18-48 Mt.	12	Retrospektiv	Gemischt	0-20 Mt.	PTSDSSI	DSM-IV 13%	AK 69%
Scheeringa et al., 2001	13-47 Mt.	15	Retrospektiv Kontrollgruppe	Gemischt	0-22 Mt.	PTSDSSI	DSM-IV 20%	AK 60%
Scheeringa et al., 2003	20 Mt. bis 6 J.	62	Retrospektiv Kontrollgruppe	Verkehrsunfälle Häusliche Gewalt Med. Prozeduren	> 2 Mt.	PTSDSSI	DSM-IV 0%	AK 26%
Scheeringa et al., 2005	20 Mt. bis 6 J.	62	Prospektiv	Verkehrsunfälle Häusliche Gewalt Med. Prozeduren	(1) >2 Mt. (2) 1 J. (3) 2 J.	PTSDSSI	DSM-IV (1) 0% (2) 2.1% (3) 11.4%	AK (1) 25.8% (2) 23.4% (3) 22.9%
Stoddard et al., 2006	12-48 Mt.	52	Prospektiv	Brandverletzungen	1 Mt.	PTSDSSI	AK: 29%	

[1]PTSDSSI: Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children (Scheeringa & Zeanah, 2005), [2]CBCL: Child Behavior Checklist (Achenbach, 1992), [3]C-GAS: Children's Global Assessment Scale (Shaffer et al., 1983), [4]PTSD-PAC: PTSD Symptoms in Preschool Children (Levendosky et al., 2002), [5]CBCL: PTSD-Skala des CBCL (Wolfe, Gentile, Michienzi, Sas, & Wolfe, 1991)

Weitere Studien untersuchten die Anzahl posttraumatischer Belastungssymptome, machen jedoch keine detaillierten Angaben zur Störungsprävalenz. Für Kleinkinder, die Zeugen häuslicher Gewalt waren, zeigt sich ein Zusammenhang zwischen den kindlichen PTBS-Symptomen und dem Schweregrad der traumatischen Erfahrung sowie den mütterlichen PTBS-Symptomen (Bogat, DeJonghe, Levendosky, Davidson, & von Eye, 2006). Ebenso besteht bei brandverletzten Kleinkindern ein signifikanter Zusammenhang zwischen dem Schweregrad des Traumas und der nachfolgenden posttraumatischen Belastungssymptomatik sowie den physiologischen Stressindikatoren (Drake et al., 2006). Brandverletzte Kleinkinder mit höheren Raten an akuten Belastungssymptomen kurz nach dem Unfall zeigen einen Monat später eine signifikante Reduktionen des sozialen Lächeln und der Vokalisation (Stoddard, Ronfeldt, et al., 2006).

2.5 Psychotherapeutische Interventionen bei traumatisierten Säuglingen und Kleinkindern

2.5.1 Standardisierte Therapieverfahren

In jüngster Zeit sind erste Versuche gemacht worden, standardisierte Therapieverfahren für den Einsatz im Säuglings- und Kleinkindesalter anzupassen und deren Wirksamkeit in dieser Altersspanne zu überprüfen. Dazu gehören vor allem Verfahren für den Einsatz bei spezifischen traumatisierten Gruppen (Cohen & Mannarino, 1993; Deblinger & Heflin, 1996; Van Horn & Lieberman, 2004; Lieberman & Van Horn, 2005). Daneben werden vielversprechende Bemühungen unternommen, den Einsatz kognitiv-behavioraler Behandlungsansätze bei traumatisierten Säuglingen und Kleinkindern unabhängig der Art der traumatischen Erlebnisse zu überprüfen (Scheeringa, Amaya-Jackson, & Cohen, 2006; Scheeringa et al., 2007).

Die *Eltern-Kind-Psychotherapie* (Van Horn & Lieberman, 2004; Lieberman & Van Horn, 2005) wurde für Säuglinge und Kleinkinder entwickelt, die Zeugen häuslicher Gewalt wurden und kann ab Geburt bis zum 5. Lebensjahr eingesetzt werden. Die grundlegende Annahme besteht darin, dass emotionale und Verhaltensprobleme im Säuglings- und Kleinkindesalter im Kontext der Beziehung mit der primären Bezugsperson anzugehen sind. Als spezifische Strategien kommen neben einer entwicklungsbezogenen Beratung, verhaltens- und

spieltherapeutische Mittel zum Einsatz. Als traumaspezifische Ziele der Eltern-Kind-Psychotherapie gelten z.B. die Förderung von adäquater Bewertung von Gefahr und Reaktionen auf Bedrohung, die Aufrechterhaltung oder Wiederherstellung der Emotionsregulation, die Wiederherstellung von Vertrauen in körperliche Empfindungen, die Wiederherstellung von Gegenseitigkeit in engen Beziehungen etc. Die Wirksamkeit der Eltern-Kind-Psychotherapie wurde in zwei kontrollierten Therapiestudien nachgewiesen. Sie zeigte sich in signifikant weniger posttraumatischen Belastungssymptomen, weniger Verhaltensproblemen bei den Kindern sowie weniger posttraumatischen Belastungssymptomen, reduziertem psychischem Stress und einer verbesserten Erziehungskompetenz bei den Müttern (Lieberman, Van Horn, & Ghosh Ippen, 2005). Eine Nachfolgestudie bestätigt die Überlegenheit der Eltern-Kind-Therapie gegenüber einer gemeindeüblichen Primärversorgung auch sechs Monate nach Abschluss der Behandlung (Lieberman et al., 2005).

Die *trauma-fokussierte kognitiv-behaviorale Therapie (TF-KBT)* (Cohen & Mannarino, 1993; Deblinger & Heflin, 1996) wurde für die Behandlung sexuell misshandelter Kinder im Vorschulalter entwickelt und kann ab 3 Jahren eingesetzt werden. Voraussetzung ist, dass die Misshandlung nicht von der primären Bezugsperson ausging. Das Verfahren besteht aus 12 individuellen und gemeinsamen Sitzungen für Kinder und Eltern. In der Kinder-Psychotherapie dient das Spiel als Kommunikationsmedium, eine Strukturierung erfolgt mittels therapeutischer Anregungen, Inputs und Reaktionen. Spezifische Interventionen sind die Identifikation von sicheren und unsicheren Situationen, dazugehörige Problemlösestrategien, Identifikation von angemessenen und unangemessenen Berührungen, Attributionen bezüglich der Misshandlung, Aufgreifen ambivalenter Gefühle gegenüber dem Täter etc. Entsprechende spezifische Interventionen bestehen auch für die Eltern-Psychotherapie. Ein Vergleich von 3- bis 6-jährigen Kleinkindern, die mit TF-KBT behandelt wurden, zeigten gegenüber einer Gruppe, die unterstützende nondirektive Therapie erhielt, hoch signifikante Verbesserungen der PTBS-Symptomatik (Cohen & Mannarino, 1996). Diese konnten auch ein Jahr nach Therapieabschluss noch beobachtet werden (Cohen & Mannarino, 1997). Die Wirksamkeit der TF-KBT bei sexuell misshandelten Kindern bestätigt eine weitere kontrollierte Therapiestudie (Deblinger, Stauffer, & Steer, 2001), die allerdings 2- bis 8jährige Kinder, also nicht nur Kleinkinder, umfasste.

Die *kognitiv-behaviorale Therapie posttraumatischer Belastungsstörungen* wurde von der Forschungsgruppe um Michael Scheeringa spezifisch für die Behandlung von PTBS bei

Säuglingen und Kleinkindern entwickelt und kann ab 3 Jahren eingesetzt werden (Scheeringa, Amaya-Jackson, et al., 2006). Das Verfahren beruht auf dem TF-KB (Cohen & Mannarino, 1996) sowie auf dem Ansatz des traumafokussierten Copings für ältere Kinder (March, Amaya-Jackson, Murray, & Schulte, 1998). Die Behandlung wird auf 12 Sitzungen aufgeteilt, deren Gestaltung in einem Manual beschrieben wird. Die Sitzungen finden gemeinsam mit dem Kind und einem oder beiden Elternteilen statt. Die ersten vier Sitzungen dienen neben der Psychoedukation einer angeleitete Identifikation und Bewertung von eigenen Gefühlen sowie der Einübung von Entspannungsübungen. In Sitzung 5 erfolgt die Erarbeitung eines Traumanarrativs – sowohl durch die Kinder als auch durch ihre Bezugspersonen. In den Sitzungen 6-10 finden graduelle Expositionen statt, welche in vivo als Hausaufgaben weitergeführt werden sollen. Sitzung 11 sieht die Rückfallprävention vor, Sitzung 12 den Therapieabschluss. Erste Untersuchungen zur Hinweise auf die Wirksamkeit dieses Behandlungsansatzes finden sich in Einzelfallbeschreibungen zweier traumatisierter Kleinkinder (Scheeringa et al., 2007). Dabei zeigte sich, dass bereits Kleinkinder in ausreichendem Maße zu Reflexion und Kooperation fähig sind. Es gelingt ihnen, sich auf strukturierte traumabezogene Expositionsübungen einzulassen und Entspannungsübungen erfolgreich einzusetzen

Als weitere Methode der Traumatherapie bietet *Eye Movement Desensitization and Reprocessing (EMDR)* explizit die Möglichkeit, traumatisierte Säuglinge und Kleinkinder ab dem ersten Lebensjahr zu behandeln. Das *Altersmodifizierte Standardprotokoll (ASP)* für Kinder bis 12 Jahre bildet die strukturelle Grundlage für die Durchführung der Behandlung. Bei Säuglingen und Kleinkindern werden spezifische Protokollaspekte ausgelassen und unter modifiziertem Setting durchgeführt, wobei jedoch kein spezifisches Behandlungsprotokoll besteht. In Hensel (Hensel, 2007) finden sich entwicklungspsychologische Überlegungen, technische Hinweise zur altersspezifischen Durchführung in den Gruppen 0-1 Jahr, 2-3 Jahre, 4-5 Jahre, 6-8 Jahre sowie die Darstellung von Fallberichten. Die Wirksamkeit der EMDR-Behandlung bei Kindern unter 6 Jahren wurde bisher noch nicht systematisch überprüft.

2.5.2 Weitere Therapieverfahren

Neben den standardisierten Therapieverfahren kommen in der Therapie traumatisierter Säuglinge und Kleinkinder auch traditionelle **Spieltherapien** zum Einsatz. Während in den ersten Lebensmonaten die Beobachtung und Überwachung des kindlichen Umgangs mit

Stimulation, die Identifikation von Übererregung hervorrufenden Reizen sowie die Entwicklung von beruhigenden Strategien im Vordergrund der Behandlung stehen, ist der Einsatz von spieltherapeutischen Ansätzen ab Ende des ersten Lebensjahres angezeigt. Traumazentrierte spieltherapeutische Ansätze sind in ihrer Praxis jedoch nicht einheitlich manualisiert. Gemeinsam ist ihnen, dass das Spiel als primäres Medium der Behandlung angesehen wird. Durch das Spiel erhält das Kind die Möglichkeit, die oft fragmentierten emotionalen und sensorischen Erinnerungen in bedeutungsvollere Narrative zu organisieren. Gleichzeitig bergen spieltherapeutische Ansätze auch die Möglichkeit zur systematischen Desensibilisierung (Gaensbauer & Siegel, 1995; Weinberg & Hensel, 2007). Eine detaillierte Beschreibung von therapeutischen Leitlinien für die Gestaltung einer traumazentrierten Spieltherapie bei Kindern bis 12 Jahren findet sich in Weinberg und Hensel (Weinberg & Hensel, 2007). Empfehlungen zum Einsatz von Spieltherapien spezifisch bei Säuglingen und Kleinkindern liegen beispielsweise für die Behandlung unfallbedingter Psychotraumata vor (Gaensbauer, 1995).

2.6 Schlussfolgerungen und Ausblick

Die heute vorliegenden Befunde zu PTBS im Säuglings- und Kleinkindesalter zeigen deutlich, dass bereits sehr junge Kinder in spezifischer Art und Weise auf traumatische Ereignisse reagieren. Je nach Studie leiden bis zu 30% der Säuglinge und Kleinkinder auch Monate bis Jahre nach dem traumatischen Ereignis an PTBS. Dabei finden sich dieselben drei Symptomgruppen wie bei älteren Kindern, nämlich Wiedererleben, Vermeidungsverhalten und Übererregung. Der Validitätsnachweis der herkömmlichen Diagnosekriterien nach DSM-IV bleibt jedoch durch die altersspezifische Ausprägung dieser Symptome und durch eingeschränkte kognitive und sprachliche Fertigkeiten in dieser Altersgruppe aus. Mit der Entwicklung von alternativen Diagnoseleitlinien für das Säuglings- und Kleinkindesalter und deren Abbildung im PTSDSSI wurde eine Möglichkeiten zur systematischen Erfassung von PTBS in dieser Altersspanne geschaffen. Die verbesserte Sensitivität für die Entwicklungsphase des Säuglings- und Kleinkindesalter geht insbesondere auf alternative Formulierungen, Weglassen oder Hinzufügen von Symptombeschreibungen, den Verzicht auf die unmittelbare beobachtbare Reaktion auf ein traumatisches Ereignis sowie die Reduktion der erforderlichen Vermeidungssymptome zurück. Im Zentrum stand das Bestreben, Symptome durch Verhaltensbeobachtung und nicht durch sprachliche Mitteilung von Gedanken und Gefühlen erfassbar zu machen. Durch die Übersetzung der englischsprachigen

Version liegt nun erstmals auch für den deutschsprachigen Raum ein handhabbares Diagnoseinstrument vor. Zusätzlich ist das PTSDSSI sowohl im englisch- wie im deutschsprachigen Raum das bis heute einzige diagnostische Verfahren, welches bereits im Säuglingsalter bzw. bei Kindern, die jünger als zwei Jahre alt sind, eingesetzt werden kann.

Für die Praxis kann insgesamt festgehalten werden, dass das PTSDSSI in Zukunft vermehrt Eingang in die Diagnostik bei Säuglingen und Kleinkindern nach traumatischen Erlebnissen finden sollte. Die frühzeitige Erfassung posttraumatischer Reaktionen ist von grosser Relevanz, da unbehandelte PTBS die gesamte weitere Entwicklung von Säuglingen und Kleinkindern beeinflussen können. Zudem liegen erste Hinweise vor, dass PTBS im Säuglings- und Kleinkindesalter zu einer deutlich höheren Persistenz neigen als dies bei älteren Kindern und Jugendlichen (Breslau, 2001) zu beobachten ist. Eingeschränkt ist die Anwendung des PTSDSSI jedoch, wenn es um die Erfassung von Reaktionen nach komplexen bzw. multiplen, wiederholten Traumatisierungen geht. In der Literatur gibt es jedoch Versuche, durch das Konzept der Entwicklungstraumastörung eine neue Diagnose zur adäquaten Erfassung von psychischen Reaktionen nach komplexen Traumatisierungen zu schaffen (Van der Kolk, 2005). Die entsprechenden Diagnosekriterien wurden in der Zwischenzeit auch in deutscher Sprache von (Landolt & Hensel, 2007) veröffentlicht.

In der Forschung lässt sich im Säuglings- und Kleinkindesalter nach wie vor ein ausgeprägtes Defizit an methodisch fundierten Studien feststellen. Wichtig erscheinen in Zukunft insbesondere Studien, in welchen unter Anwendung des PTSDSSI verschiedene Gruppen traumatisierter Säuglinge und Kleinkinder näher untersucht werden. Von ebensolcher Relevanz sind prospektive Studien zum Verlauf von PTBS und deren Auswirkungen auf die kindliche Entwicklung. Auch das Zusammenspiel der verschiedenartigen Prädiktoren ist im Säuglings- und Kleinkindesalter noch weitgehend unerforscht und könnte interessante Unterschiede zu älteren Kindern und insbesondere zum Erwachsenenalter zeigen. Schliesslich besteht ein grosser Nachholbedarf in der Entwicklung und Überprüfung von spezifischen Interventionen zur Behandlung von PTBS im Säuglings- und Kleinkindesalter.

3

Posttraumatic stress and behavior problems in infants and toddlers with burns

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Abstract

This study assessed posttraumatic stress disorder (PTSD) and behavior problems in young children with burns and examined individual, injury-related, and family-related determinants. Seventy-six children, age 12-49 months, were assessed at an average of 15 months after their burn injury, using parents as informants on the *Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children* and the *Child Behavior Checklist*. Ten children (13.2%) met the alternative criteria for PTSD proposed by Scheeringa et al. Number of PTSD symptoms was associated with family-related variables (maternal PTSD, quality of family relations). Compared to community norms, children with burns showed less externalizing problem behavior, and internalizing problem behavior was within the normal range. Overall, behavioral adjustment was associated with the quality of family relations (cohesion, expressiveness, conflicts). Whereas behavior was found to be normal in young children with burns, this study provides evidence for a substantial prevalence of PTSD.

3.1 Introduction

There is now clear evidence that trauma affects young children in a way similar to the way it affects older children and adults (Scheeringa, 2008). However, diagnosing posttraumatic stress disorder (PTSD) in young children using DSM-IV diagnostic criteria and algorithms (American Psychiatric Association, 2000) is difficult, since the criteria rely explicitly on verbalizations of subjective experiences. Furthermore, posttraumatic stress symptoms in young children may differ in their clinical manifestation from those in older children and adults (Scheeringa, 2004). Sound measures that include behaviorally-anchored and developmentally-sensitive alternative criteria for diagnosing PTSD in preschoolers have been developed recently (Scheeringa et al., 2001; Scheeringa et al., 2003; Scheeringa & Zeanah, 2005b). Therefore, studies examining posttraumatic stress in infants and toddlers after different traumatic events, such as road traffic accidents and gas explosion and burn injuries, have emerged only just recently (Ohmi et al., 2002; Drake et al., 2006; Stoddard, Ronfeldt, et al., 2006; Stoddard, Saxe, et al., 2006; Meiser-Stedman et al., 2008).

A severe burn injury is one of the most traumatic injuries experienced by children (Saxe et al., 2005). Traumatic aspects include not only the injury event but also the difficult period of treatment and hospitalization involving painful and frightening experiences. Despite the fact that infants and toddlers account for about 50% of all pediatric burn injuries (Schiestl et al., 2006), very few studies on psychosocial outcome have included preschoolers. Recently, a U.S. research group started to focus on the short-term impact of serious burn injuries in preschoolers and to assess the occurrence of acute stress symptoms using the *Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children* (Stoddard, Saxe, et al., 2006). Almost 30% of these young children exhibited acute stress symptoms within 1 month after the burn incident. Factors contributing to the development of acute stress symptoms were indicators of trauma severity and parents' PTSD symptomatology (Drake et al., 2006; Stoddard, Ronfeldt, et al., 2006). Further, the positive effect of morphine on decreasing the number of PTSD symptoms in young children with burns (Stoddard et al., 2009) supports the traumatizing effect of pain experiences. Along with these studies on acute stress symptoms, there are two studies that examined behavior problems in preschoolers after burn injuries using the Child Behavior Checklist (CBCL). The first, a study by Meyer, Robert, Murphy and Blakeney (2000) of 33 children age 2-3 years, revealed that young burn survivors with a mean burn size of 50% exhibited significantly more internalizing behavior problems than children from a community sample. In contrast, results

from a controlled, prospective study in 40 burn survivors age 4 years and younger (mean burn size: 8.5%) found normal behavior (Kent et al., 2000).

In summary, although there are now some initial insights into acute stress symptomatology and behavior problems of young children with burns, this is certainly not true for long-term PTSD. Specifically, the frequency rate of PTSD in this age group is still unknown. Also, factors predicting PTSD and behavior problems in the long-term after a burn injury have not yet been examined. The present study had two objectives: First, we aimed to assess the frequency of PTSD according to the DSM-IV and the alternative criteria (Scheeringa et al., 2003) for young children and to assess the presence of behavior problems in a small community-based sample of preschoolers with burns. Due to the greater age sensitivity of the alternative diagnostic algorithm, we hypothesized higher rates of PTSD according to the alternative algorithm compared to the DSM-IV algorithm. Based on previous findings in preschoolers with similar burn sizes (Kent et al., 2000) and school-age children (Landolt, Grubenmann, & Meuli, 2002), we expected behavior problems in our sample to be within normal ranges as compared to published community norms. Second, we aimed to examine the association of individual, injury-related, and family-related characteristics with the total number of PTSD symptoms and behavior problems. Following the few existing studies on acute stress in preschoolers with burns, we expected to find a substantial influence of injury-related variables on the child's psychological outcome. Investigations on posttraumatic adaptation in early childhood emphasized the importance of the parent-child relationship in modulating the effects of a traumatic event (Scheeringa & Zeanah, 2001). This was recently confirmed for preschoolers with burn injuries during the treatment phase (Saxe et al., 2006). In this context and on the basis of previous findings in school-age children with burns (Landolt, Grubenmann, et al., 2002), we expected to find a substantial influence of family-related characteristics such as parental well-being and family environment characteristics.

3.2 Methods

3.2.1 Procedure

The study was approved by the institutional review board. Parents of young children age 9-48 months were eligible for the study if the following criteria were met: (a) hospitalization of at least one night for a burn injury at the largest Swiss Pediatric Burn Center of University Children's Hospital Zurich, (b) at least 3 months post-burn in order to avoid interference by medical problems (e.g., pain, surgery), (c) child living at home for at least 1 month after

discharge from hospital in order to avoid the assessment of acute post-hospital adjustment problems, (d) no previous evidence of mental retardation, (e) parental command of the German language. A total of 101 eligible parents were invited by letter to participate in the study. Of these, 25 parents refused to participate. The final sample comprised 76 participants (response rate 77%). There were no significant differences between participants and non-participants with regard to child age at injury (Mann-Whitney U = 855.50, p = .46), time lapse post-burn (Mann-Whitney U = 729.50, p = .08), burned total body surface area (Mann-Whitney U = 729.50, p = .23), and length of hospital stay (Mann-Whitney U = 822.00, p = .31). After we received parents' written informed consent, we contacted them by telephone and scheduled a face-to-face interview for the 76 mothers to assess PTSD symptoms of their children. Most interviews were conducted at the child's home. Additionally, mothers answered separate questionnaires on their child's behavior problems, on family characteristics, and on their own PTSD symptoms. Fathers answered separate questionnaires on their own PTSD symptoms. Both parents were requested to return their questionnaires within two weeks after the interview. Sixty-one mothers and 54 fathers returned the questionnaires within the requested time or shortly after being reminded. Demographic and injury-related variables were retrieved from the patient's medical record.

3.2.2 Sample Characteristics

Seventy-six children (44 boys, 32 girls) with a mean age of 32.0 months (SD = 9.5; range 12-49) participated in the study. Socioeconomic status (SES) of the families was as follows: 8 lower SES (11.4%), 41 middle SES (58.6%), 21 upper SES (30%). In 6 cases, SES was unknown. In 41 children (56.2%) both parents were Swiss; 32 (43.8%) had a background of foreign nationality (either one parent was Swiss and the other a foreign national (13 children, 17.8%) or both parents were foreign nationals (19 children, 26%)); in 3 cases nationality was unknown. Mean age at burn injury was 16.5 months (median = 15, SD = 9.8; range 0-44). Burns were most frequently the result of scalds (90.8%). Average time lapse post-burn was 14.8 months (SD = 9.2; range 3-48). Mean burn size was 7.6% (SD = 7.4, median = 5.5%: range 1-50%). Thirty percent of the participants had at least one skin grafting procedure. Twenty-nine percent of the children needed dressing changes under general anesthesia during hospitalization (mean number of dressing changes = 3.1; SD = 2.5, median = 1.5; range 1-13). The average length of hospital stay was 14.5 days (SD = 20.1, median = 7, range 1-126).

3.2.3 Measures

Child Posttraumatic Stress Symptoms. PTSD symptoms were assessed using the German translation (Irblich et al., 2006) of the *Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children* (PTSDSSI) (Scheeringa & Zeanah, 2005b). Translation of the instrument was performed according to international guidelines (Mallinckrodt & Wang, 2004), including independent back-translation and authorization by the original authors of the scale. The PTSDSSI is an examiner-based interview that is conducted with the child's primary caregiver; it is based on the studies by Scheeringa et al. (Scheeringa et al., 1995; Scheeringa et al., 2001; Scheeringa et al., 2003). It contains all of the DSM-IV PTSD items as well as modified wordings for five PTSD symptoms (recollections, flashbacks, diminished interests, detachment, and irritability) to make them more developmentally sensitive for children age 9 months to 6 years. As an example of this modification for preschool children, item one of criterion B (recollection) contains an additional note that intrusive recollections in young children do not necessarily appear distressing and that in young children repetitive play may occur in which themes or aspects of the trauma are expressed. The coding of parents' answers into PTSD symptoms was conducted according to the coding manual by Scheeringa & Zeanah (2005). The PTSDSSI allows for a diagnosis either by the DSM-IV algorithm or by the empirically validated alternative algorithm for young children. The latter does not require criterion A2 (the child's reaction at the time of the event). Only one of three items is needed to meet the avoidance/numbing criterion. Symptoms must have been present for at least 1 month and cause impairment in at least one significant life area. The total number of PTSD symptoms can be determined by summing up all symptoms present. In order to clarify the picture of the PTSD symptoms displayed by the children in this study, the content of each symptom affirmed by caregivers during the interview was coded into injury-related, treatment-related, or mixed/unspecific and then summed up for the two clusters of avoidance/numbing and intrusion. Good interrater reliability and validity of this measure were confirmed in several studies (Scheeringa et al., 2001; Scheeringa et al., 2003, 2005). In this study, the sum score of total number of PTSD symptoms had an internal consistency of Cronbach's $\alpha = 0.65$.

Child Behavior Problems. The *Child Behavior Checklist 1½-5* (CBCL/1½-5) (Achenbach & Rescorla, 2000) is a 100-item standardized parent-report measure of behavior and emotional problems in children. Higher scores indicate a greater number and intensity of behavior and emotional problems. In this study the German version was used (Arbeitsgruppe Deutsche Child Behavior Checklist, 2002), and only parents of children older than age 18 months were

asked to fill in the questionnaire. Reference T-scored values are provided by a community sample of 700 healthy U.S. children age 18-71 months. To date, no Swiss norms for the CBCL/1 ½-5 are available. A cut-off T-score of 65 was used to indicate behavior problems in the borderline/clinical range (Achenbach & Rescorla, 2000). The CBCL was previously shown to have excellent reliability and validity (Achenbach & Rescorla, 2000). Internal consistency coefficients in this study are reported in Table 6 and were similar to those of the reference study.

Parents' Posttraumatic Stress Symptoms. PTSD symptoms of mothers and fathers were assessed using the *Posttraumatic Diagnostic Scale* (PDS) (Foa et al., 1997). The scale is widely used for screening and assessing PTSD in clinical and research settings, and it demonstrated excellent psychometric properties in its original English version (Foa et al., 1997). This study used the German version of the PDS (Steil & Ehlers, 2000), which demonstrated similar psychometric properties to the original English-language scale. In our sample, internal consistency of the PDS total score was $\alpha = .77$ for fathers and $\alpha = .83$ for mothers.

Family Relations. Quality of family relations was measured using the German version (Schneewind et al., 1985; Moos & Moos, 1994) of the *Family Relationship Index* (FRI) (Schneewind et al., 1985; Moos & Moos, 1994). The 27-item questionnaire consists of three subscales of the Family Environment Scale, assessing cohesion, expressiveness, and conflict. The FRI overall index is calculated by summing the three subscales, whereby items of the conflict scale are reversely scored. Higher scores indicate better family relationships. Reliability and validity of this scale were confirmed in previous studies (Moos & Moos, 1994). Internal consistency of the overall index was $\alpha = .69$.

Socioeconomic Status. SES was calculated by means of a 6-point scale of both paternal occupation and maternal education (range 2-12). Specific examples of educational and occupational levels were defined in a previous study at University Children's Hospital (Largo, Molinari, Comenale, Weber & Duc, 1989). Maternal education was used, because in Switzerland mothers of young children often resign from their jobs and stay at home with their children. Three socioeconomic classes were defined as follows: scores 2-5 as lower SES; scores 6-8 as middle SES; scores 9-12 as upper SES. This measure was shown to yield a reliable and valid indicator of SES in the Swiss community (Landolt, Vollrath, & Ribi, 2002).

Preceding Life Events. The occurrence of 12 significant life events such as divorce, unemployment, or severe illness in the family was assessed from mothers for the 12 months

preceding the burn injury (Landolt & Vollrath, 1998). A life event score for each family was computed by counting the number of life events reported.

Trauma Severity Score. A trauma severity score similar to the one used by Drake et al. (2006) was computed by grouping the variables "burn size," "number of dressing changes," and "length of hospital stay" into three equal categories. The child's burn size was categorized as small (1 = 1-3%), medium (2 = 4-7%), or large (3 = above 7%). Dressing changes were categorized as low frequency (1 = 1 dressing change), medium frequency (2 = 2-3 dressing changes), or high frequency (3 = more than 3 dressing changes). Length of hospital stay was categorized as short (1 = 1-5 days), medium (2 = 6-11 days), or long (3 = more than 11 days). The average trauma severity score for each child was computed by summing up the scores and dividing the sum by three. Internal consistency of the trauma severity score was $\alpha = .70$.

3.3 Statistical Analysis

Data were analyzed using SPSS statistical software for Windows, release 16.0 (SPSS Inc., Chicago, Illinois). Analyses were performed with two-sided tests, with $p < .05$ considered significant. Descriptive statistics were used to analyze the frequency of PTSD symptoms and diagnosis. Discrepancy between two different frequency rates of PTSD was tested by means of chi-square analysis. Comparison of CBCL T-scores with published reference data was determined using one-sample *t*-tests. In addition, effect sizes of group differences (Cohen's d) were computed for the CBCL scales. According to the Kolmogorov-Smirnov Goodness of Fit test, some independent variables were not normally distributed. Therefore, associations of the total number of PTSD symptoms and behavior problems with individual, injury-related, and family-related characteristics were examined by means of nonparametric Spearman rank correlations. Holm's Sequential Bonferroni Procedure was applied in order to correct for multiple comparisons (Abdi, 2010). Mann-Whitney U-tests were used to determine differences in PTSD symptoms and behavior problems when the independent factors were dichotomized.

3.4 Results

3.4.1 Posttraumatic Stress Disorder

Of the 76 infants and toddlers in the study, 10 (13.2%) (95% CI 5.6-20-8) met full criteria for a diagnosis of current PTSD based on the alternative algorithm for young children

(Scheeringa & Zeanah, 2005b). Notably, only one child (1.3%) (95% CI -1.25-3.9) met the original DSM-IV criteria for a diagnosis of PTSD. Pearson's chi-square test revealed a significant difference between the frequency of PTSD when diagnosed with the alternative, respectively DSM-IV algorithm ($\chi^2 = 6.272$, df = 1, p = 0.01). Analysis of symptom clusters of PTSD revealed that 73.7% of the 76 children met the alternative criteria for reexperiencing, 64.5% for avoidance and emotional numbing, and 19.7% for increased arousal. Examination of the specific content of PTSD symptoms showed that reexperiencing and avoidance/numbing symptoms were more often treatment-related (e.g., distress due to people wearing white clothes, distress when being held or touched in the body area of the injury, avoidance of certain rooms/areas in the hospital, etc.) than related to the injury event (e.g., distress due to the sound of the kettle, distress when someone spills something, avoidance of the place where injury occurred, etc.) (see Table 5). One-quarter to one-third of the children showed a mixture of both treatment and event-related symptoms in the reexperiencing and the avoidance/numbing symptom cluster. Full diagnosis of parental PTSD occurred in 6.9% (n = 4) of the mothers and 6% (n = 3) of the fathers.

Table 5 Content of symptoms in children with at least one PTSD symptom

Content of PTSD symptoms	**Avoidance/numbing symptoms (n = 49)**	**Intrusion symptoms (n = 56)**
Related to injury event (%)	26.5	19.6
Related to treatment (%)	36.8	41.1
Mixed/unspecific (%)	36.7	39.3

3.4.2 Behavior Problems

As listed in Table 6, mothers reported significantly lower rates of externalizing and total problem behavior in their children compared to community norms. Effect sizes of mean differences were small to medium. Analysis of T-scores revealed that only 5.1% of the young children with burns had internalizing and 3.4% had externalizing behavior problems in the borderline/clinical range.

Table 6 Sample means and normative data for behavior problems in children older than age 18 months (CBCL T scores)

Child Behavior Checklist (α)	Patients (n = 59)	Reference group[a] (n = 700)	Effect size		Above Cut-off (>=65)
	Mean (SD)	Mean (SD)	D	p[b]	(%)
CBCL Total Score (.85)	46.86 (9.2)	50 (10)	-.33	**≤.01**	3.4
CBCL Internalizing Score (.77)	47.54 (9.8)	50 (10)	-.25	.06	5.1
CBCL Externalizing Score (.72)	46.15 (8.6)	50 (10)	-.41	**≤.01**	3.4

Note. [a] Community norms (Arbeitsgruppe Deutsche Child Behavior Checklist, 2002), [b] one-sample t-test with community norms.

3.4.3 Determinants of PTSD Symptoms and Behavior Problems

Table 7 shows associations between individual, injury-related, and family-related variables with the total number of PTSD symptoms and the CBCL total T-score. Individual variables such as child's age at assessment and child's age at time of injury were not related to PTSD and behavior problems. As an injury-related factor, trauma severity was significantly correlated with the child's PTSD symptoms. However, after correction for multiple comparisons, the association was no longer statistically significant. Injury-related factors were not significantly correlated with behavior problems. The importance of family-related variables became apparent in significant associations between the child's PTSD symptoms and both maternal PTSD symptoms and the quality of family relations (i.e., cohesion, expressiveness and conflicts within the family). These associations remained significant after correction for multiple comparisons. The relation between father's PTSD symptoms and child's outcome did not reach statistical significance.

Table 7 Spearman correlation coefficients between the total number of PTSD symptoms, behavior problems, and individual, injury-related, and family-related variables

	Number of PTSD symptoms	CBCL Total behavior problems T-Score
Individual variables		
Age at assessment	.13	-.06
Age at burn injury	.15	.13
Injury-related variables		
Place of burn injury at home	-.12	-.07
Time lapse post-burn	.01	-.19
Trauma severity score (α = .70)	**.23***	-.02
Family-related variables		
SES (Sum score)	.11	.01
Preceding life events	.08	.15
Number of PTSD symptoms, mother	**.39** (#)**	**.29***
Number of PTSD symptoms, father	.19	.26
Family Relationship Index	**-.41** (#)**	**-.43** (#)**

Note. *unadjusted $p \leq 0.05$, ** unadjusted $p \leq 0.01$, (#) significant at the $p \leq 0.05$ level after Holm-Bonferroni correction.

3.5 Discussion

This cross-sectional study assessed long-term PTSD symptomatology and behavioral maladjustment in preschoolers with burns by employing a developmentally appropriate approach. Further, we examined predictors of children's post-burn symptomatology. Although a few previous studies reported acute stress symptoms in this age group, this study is the first to report valid long-term PTSD rates in preschoolers with burns on average 15 months after their injuries. In agreement with our initial hypothesis, the reported frequency rate of 13.2% according to the alternative criteria by Scheeringa et al. significantly exceeds the DSM-IV rate of 1.3%. Regarding the numerous symptoms displayed by the children in our sample, a frequency rate of 13.2% based on the alternative algorithm criteria not only

seems more appropriate but also shows more agreement with other studies on injured preschoolers than a DSM-IV rate of 1.3% (Meiser-Stedman et al., 2008). In our study 73.7% of the 76 infants and toddlers met the alternative reexperiencing criterion, 64.5% met the avoidance/numbing criterion, and 19.7% met the increased arousal criterion. These findings contrast with results from studies using the DSM-IV algorithm, where the avoidance/numbing criterion is usually the least prevalent. The relatively high frequency of avoidance/numbing symptoms in our sample can be attributed to the varying PTSD algorithm threshold. Studies using the alternative diagnostic algorithm for PTSD in infants and toddlers, where only one item instead of three items is mandatory to meet the avoidance/numbing criterion, demonstrate the same order of frequencies (Stoddard, Saxe, et al., 2006).

Besides PTSD, this study assessed behavior problems as another important outcome variable. In contrast to a previous study of young burn survivors (Meyer et al., 2000), mothers in our sample reported significantly fewer externalizing behavior problems and total behavior problems in their children as compared to healthy children. The rate of internalizing behavior problems was within the normal range. However, mean burn size in the study by Meyer et al. (2000) was substantially higher (50%) than in our study of a less severely injured sample (7.6%). Previous studies that included preschoolers with comparable burn size (Kent et al., 2000) and studies on school-age children (Landolt, Grubenmann, et al., 2002) reported normal behavior and are therefore in line with our findings on internalizing behavior problems. The absence of behavior problems despite enhanced levels of PTSD symptoms is also known from a study in school-age children (Lengua, Long, Smith, & Meltzoff, 2005; Vermunt et al., 2008). Beyond that, negative and positive psychological sequelae of traumatic experiences can coexist, as demonstrated in a recent study (Alisic, Van der Schoot, Van Ginkel, & Kleber, 2008). However, the findings on significantly fewer externalizing and total behavior problems call for further explanations. One possible clue to this positive behavioral outcome might be the extensive parental care and attention that young children with burns usually receive. Although characteristics of parental care and attention were not directly assessed in this study, the significant association between behavioral adjustment and the quality of family relations as shown in Table 7 might further underline this assumption. This mechanism might reflect the concept of “posttraumatic growth” in children and/or in parents, which refers to the experience of positive change as a result of the struggle with a life crisis (Alisic et al., 2008). In this context, children might have shown fewer behavior problems or parents might have perceived them as less striking and disturbing. However, several researchers suggested that excellent psychological adjustment may in fact be a false-positive finding, in that parents

form an overly optimistic picture of themselves as a result of defense mechanisms during the adjustment process (Abdullah et al., 1994). Finally, results might have been more specific if we had used a structured psychiatric interview such as the Preschool Age Psychiatric Assessment (PAPA) (Egger & Angold, 2004) instead of a checklist measure identifying only broad domains of problems. The findings thus need to be explored further in future studies.
We also aimed at examining various correlates of PTSD and behavior problems. After correction for multiple comparisons we found no significant associations between injury-related variables and the child's PTSD symptoms and behavior problems. In this regard, our findings contradict our initial hypothesis and differ from the results of earlier studies on acute stress in preschool children with burns (Drake et al., 2006; Stoddard, Saxe, et al., 2006). However, those earlier studies assessed acute stress symptoms within the first month after admission to the hospital. It can be assumed that in this acute phase injury-related factors are more important compared to the long-term phase that we examined in our study. Furthermore, a path analyses model in the study by Stoddard et al. (2006) revealed only an indirect influence of injury-related variables on the child's acute stress symptoms. Notably, uncorrected bivariate correlations in our study revealed a significant relation between trauma severity and the number of child's PTSD symptoms. Considering the variables that were included in our trauma severity score, it is conceivable that injury-related variables could indeed have a traumatizing effect on young children. The mainly treatment-related content of the child PTSD symptoms in our study also support this hypothesis. As a result of their developmental stage, it might be more difficult for infants and toddlers to understand the necessity for painful medical procedures and the temporary separation from care givers. For example, clinical experience shows that young children may interpret burn dressing changes as an act of aggression. Young children's limited understanding may therefore exacerbate the subjective feelings of fear, horror, and helplessness that render an event traumatic. Finally, the lack of a significant association between time lapse post-burn and the development of PTSD is in line with findings of a previous study (Scheeringa et al., 2005) and possibly indicates the risk of an unremitting course of PTSD in young children with burns.
The influence of family-related variables becomes apparent in significant associations between child's outcome and mothers' own PTSD as well as the quality of family relations. Furthermore, behavior problems were significantly related to the quality of family relations. To date, the importance of family-related variables for psychological adjustment has never been reported for this age group. However, similar results were found in older children (Landolt, Grubenmann, et al., 2002). Furthermore, our findings about the possible protective

influence of maternal well-being and good family relations on the development of child's PTSD and behavior problems are in line with previous findings in preschool children with traumatizing experiences (Scheeringa et al., 2001; Stoddard et al., 2006). However, in our study reported child adjustment, mother's PTSD symptoms, and quality of family relations were assessed by the same person. Therefore, it is possible that these reports are related (shared variance). The lack of significant association between father's and child's PTSD symptoms could affirm this association. Another possible clue to this lacking effect of paternal PTSD might be the fact, that in this age group of young children, usually mothers are mainly responsible for the child's care and therefore might have been more often present during the child's hospitalization than fathers. Furthermore, it cannot be excluded that non-participating fathers (n = 22) might have differed from participating fathers concerning their PTSD symptoms. However, participation of fathers was not significantly related to the child's PTSD (Mann-Whitney U = 580.00, p = .87) and behavior problems (Mann-Whitney U = 132.00, p = .25).

The strengths of this study include the relatively large sample, the standardized clinical assessment, the high rate of participation (77%), and the inclusion of fathers. Nonetheless, some limitations merit note. First, the results of this study are relevant to hospitalized young children with burns of small to moderate sizes. Due to the cross-sectional design, interpretation of causal relations between outcome and predictor variables requires caution. Second, data based on parental questioning provide only select information. Since the child's symptoms were rated by mothers, a possible influence of maternal distress on the perception and rating of their child's symptoms must be considered. However, in our sample, only 6% of mothers met criteria for a PTSD diagnosis themselves. Moreover, maternal ratings of their children's behavioral adjustment were very positive and revealed only few problems. Third, due to the lack of Swiss norms, we used U.S. norms to interpret the behavior of Swiss preschoolers. The appropriateness of U.S. norms for our sample can be questioned. However, previous studies on the CBCL for preschoolers support the use of the U.S. norms for German samples (Phoebe, 2003) and its cross-cultural validity (Koot, Van Den Oord, Verhulst, & Boomsma, 1997; Hannesdottir, Sourander, & Piha, 2000). Therefore, we believe that the use of U.S. norms for our sample is appropriate. Finally, although we assessed several individual and injury-related determinants of PTSD and behavior problems, other possibly important variables, such as pre-traumatic psychopathology and health status, were not considered.

Several implications for the clinical care of young children with burns can be drawn from this study. First, our findings add to the recently emerging evidence that even very young children

develop long-lasting symptoms of PTSD after traumatic experiences such as injury events and invasive medical procedures. Second, the assessment of specific PTSD symptoms is especially relevant in young children after traumatic events, since common instruments such as the CBCL seem to underestimate young children's posttraumatic stress reactions. Third, the results of this study lead us to believe that family-related characteristics may play an important role in the development of PTSD symptoms in young children. Therefore, interventions that target the parents' own distress as well as the family system are needed to reduce posttraumatic stress morbidity in young children with burn injuries.

4

Posttraumatic stress in infants and preschoolers with cancer

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Abstract

This study is the first to assess posttraumatic stress disorder (PTSD) in young children with cancer and to examine individual, medical, and parent-related determinants. Forty-eight patients with cancer, ages 8-48 months, were assessed an average of 15 months after their diagnosis, using mothers as informants to complete the *Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children*. Additionally, mothers and the attending pediatric oncologist completed questionnaires on various determinants of child PTSD. Nine children (18.8%) met the age-appropriate criteria for full PTSD proposed by Scheeringa et al., and 20 children (41.7%) met criteria for partial PTSD. Multivariate logistic regression analysis revealed that higher child age at diagnosis (odds ratio = 1.11) and maternal PTSD severity (odds ratio = 1.14) increased the risk of full or partial PTSD in children. This study provides evidence for a substantial prevalence of PTSD in young children with cancer and identified important risk factors.

4.1 Introduction

The treatment of childhood cancer has been increasingly successful in recent decades. Improved survival due to multimodal treatment regimens has placed emphasis on the psychological sequelae of cancer treatment, which involves invasive medical procedures, treatment-related side effects like pain, loss of hair, and prolonged periods of hospitalization. Accordingly, the experience of a life-threatening illness has been added to the list of stressful events for posttraumatic stress disorder (PTSD) in the Diagnostic Statistical Manual of Mental Disorders, 4th edition (DSM-IV) (American Psychiatric Association, 2000).

In recent years, a growing body of research has demonstrated trauma-related symptomatology, such as intrusive thoughts, avoidant behaviors, and increased physiological arousal in school-age children with cancer. Most studies have focused upon survivors, with only a few studies including patients on active treatment. The rates of PTSD in patients on active treatment have ranged from 10% (Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003) and 13% (Currier, Jobe-Shields, & Phipps, 2009) to over 21% (Butler, Rizzi, & Handwerger, 1996). While some studies have illustrated substantial levels of partial PTSD (Bruce, Gumley, Isham, Fearon, & Phipps, 2011), others have failed to identify differences between children with cancer and healthy peers (Barakat et al., 1997). Regarding predictors of PTSD, recent studies in older children have found female sex, late physical effects, subjective threat appraisal, and family functioning to be important variables (Bruce, 2006). Interestingly, most studies revealed no significant associations between objective medical data regarding illness or treatment severity and a child's PTSD (Bruce, 2006). However, predictors are hardly studied on the basis of a theoretical background, since etiological theories on PTSD in children and their empirical validation remain scarce (Alisic et al., 2011).

While the psychological impact of cancer has been widely studied in school-age children and their families, research on children below the age of four years is almost non-existent. Current scientific knowledge is limited to a single case study, which reports on PTSD in a 5-month-old boy with cancer. Specific risk factors could not be identified in this single case (Roy & Russell, 2000).

This lack of knowledge is a significant limitation, since there is a peak cancer incidence in the first four years of life (Mitter et al., 2011). Even though infants and preschoolers might be too young to understand the life-threat associated with cancer, the experience of pain, temporary separation from caregivers, changes in daily life routine due to prolonged periods of

hospitalization, and changes in their caregiver's emotions are potentially traumatizing for very young children (Kazak & Baxt, 2007).

Over the last 20 years, an expanding number of researchers have started to investigate infants and preschoolers who are exposed to different types of trauma, like domestic violence (Levendosky et al., 2002), burns (Graf et al., 2011), motor-vehicle-accidents (Meiser-Stedman et al., 2008), terrorism (DeVoe, Bannon, & Klein, 2006) and hurricanes (Scheeringa & Zeanah, 2008). Meanwhile, there is clear evidence that young children present with similar patterns of PTSD as older children. However, assessing and diagnosing PTSD in young children using DSM-IV diagnostic criteria (American Psychiatric Association, 2000) is difficult, since the criteria rely explicitly on verbalizations of subjective experiences. Furthermore, young children with PTSD may exhibit different clinical manifestations than older children (Scheeringa, 2004). Pioneering research by Scheeringa and colleagues (Scheeringa et al., 2001; Scheeringa et al., 2003; Scheeringa & Zeanah, 2005b) has led to the development of alternative PTSD criteria and a diagnostic algorithm for infants and preschoolers. This involved the modification of DSM-IV PTSD symptom wordings in order to make them behaviorally-anchored and developmentally-sensitive. Furthermore, developmentally-relevant symptoms have been added (e.g., loss of previously-acquired developmental skills), while others have been excluded (e.g., sense of foreshortened future). Finally, an alternative diagnostic algorithm has been proposed to reliably diagnose PTSD in children of 6 years of age or younger. Criterion A2 (child's response of intense fear, helplessness or horror to the traumatic event) has been dropped, since preverbal children are not able to report on their reaction when an adult is not available to witness it. The most important difference is the lowering of required criteria in the avoidance symptom cluster (criteria/cluster C). Since many of these cluster C symptoms are internalizing phenomena that are difficult to detect in young children, the diagnostic threshold has been lowered from three to one symptom. The appropriateness of this change has been confirmed in several studies (Scheeringa, Zeanah, et al., 2011).

In summary, there is a complete lack of knowledge regarding the rate of occurrence and risk factors of PTSD in infants and preschoolers with cancer. Therefore, the present study had two objectives. First, we aimed to assess the prevalence of PTSD, as defined by the alternative diagnostic criteria for young children (Scheeringa et al., 2003), in infants and preschoolers with cancer. Based upon findings in school-age children, we expected rates of PTSD between 10 and 20%. Second, we sought to examine determinants of child PTSD. Based on the

transactional trauma adaptation model (Landolt, 2003) we wanted to study associations between PTSD and individual, medical, and parent-related characteristics. Following the findings of previous studies in school-age children, we expected female sex to be associated with PTSD. However, we expected treatment intensity, as an objective indicator of trauma severity, to play a subordinate role in the prediction of child PTSD. Moreover, we hypothesized that parent-related characteristics, such as maternal well-being, would have an influential effect.

4.2 Patients and Methods

4.2.1 Participants and Procedures

Young children with cancer, ages 8-48 months, were eligible for the study if the following criteria were met: (a) hospitalization at the University Children's Hospital Zurich; (b) at least 3 months since diagnosis, in order to avoid the assessment of acute adjustment problems; (c) no previous evidence of mental retardation; and (d) parents are German speaking. Parents of eligible children were invited consecutively by letter to participate in the study over a period of two years. Of 52 eligible children, four families refused to participate. The final sample consisted of 48 children (response rate 92%). There were no significant differences between participants and non-participants with regard to the child's age at diagnosis ($U=76.5$, $p=.50$), type of treatment ($U=82.0$, $p=.42$), or cumulative days of hospital stay ($U=70.0$, $p=.37$). Due to ethical restrictions no further medical variables were available for non-participants. After receiving written informed consent from the parents, a face-to-face interview with the mothers was scheduled. Interviews were conducted at the child's home (n=30), at the office of the interviewing psychologist (n=15), at the mother's working place (n=1), or by telephone (n=2). Additionally, mothers answered separate questionnaires on the parents' nationality, the family's socioeconomic status, and their own PTSD symptoms, and were asked to return their questionnaires within two weeks of the interview. Because five mothers did not return their questionnaires, data on maternal characterstics are available for only 43 cases. The attending pediatric oncologist answered a questionnaire on the child's diagnosis and treatment within a week of the interview. Sociodemographic variables were retrieved from hospital records. The study was approved by the local institutional review board.

4.2.2 Measures

Child posttraumatic stress symptoms: PTSD symptoms were assessed using the German version (Irblich et al., 2006) of the *Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children* (PTSDSSI) (Scheeringa & Zeanah, 2005b). The PTSDSSI is an examiner-based interview that is conducted with the child's primary caregiver. The measure assesses whether the child has experienced 11 specific traumas or an additional trauma. The mothers were asked to answer the questions in reference to the trauma of cancer diagnosis and treatment. The interview contains all of the DSM-IV PTSD items, such as exposure to traumatic stressors (criterion A), symptoms related to re-experiencing traumatic situations (symptom cluster B), symptoms of avoidance of stimuli associated with the trauma and numbing of general responsiveness (symptom cluster C), and symptoms of increased arousal (symptom cluster D).

In order to improve the sensitivity of the items for children ages 9 months to 6 years, the interview contains modified wordings for five PTSD symptoms (recollections, flashbacks, reduced interests, detachment, and irritability). As an example of this modification, item one of symptom cluster B contains an additional note that intrusive recollections in young children do not necessarily appear distressing; and that young children may engage in repetitive play during which themes or aspects of the trauma are expressed (so-called *traumatic play*). Responses of caregivers reflect the frequency with which each symptom is observed on a 3-point Likert scale, ranging from 0 (none during the past month) to 2 (often during the past month). When endorsed, examples must be provided. Follow-up questions and clarifications are used until the interviewer is persuaded that the symptom is present and as severe as indicated. Examples from the manual by Scheeringa & Zeanah (Scheeringa & Zeanah, 2005a) further facilitate coding parental responses into PTSD symptoms.

The PTSDSSI yields a diagnosis either by the DSM-IV algorithm or by the alternative algorithm for young children (Scheeringa, 2011b). The latter does not require criterion A2 (the child's reaction at the time of the event). Only one instead of three symptoms is required to meet the cluster C. Symptoms must have been present for at least one month (criterion E) and cause impairment in at least one significant life area (criterion F); e.g., they must prevent the child from doing things with the family or other children or get in the way with activities in the house.

Good inter-rater reliability and validity of this measure have been confirmed in several studies (Scheeringa et al., 2001; Scheeringa et al., 2003, 2005). In addition to a full diagnosis of PTSD, the current study also assessed partial PTSD which was defined in a conservative,

restrictive fashion (Stein, Walker, Hazen, & Forde, 1997). Children were required to have at least one symptom in each of the three PTSD symptom clusters. The mean symptom severity of each symptom cluster, as well as of all the PTSD symptoms, was calculated by summing up the frequency scores (1, 2) and dividing that sum by the number of symptoms from each cluster, respectively, across the entire instrument (Cronbach's α=.71).

Parents' Posttraumatic Stress Symptoms: PTSD symptoms of mothers were assessed using the German version (Griesel, Wessa, & Flor, 2006) of the *Posttraumatic Diagnostic Scale* (PDS) (Foa et al., 1997). This scale is widely used for assessing PTSD in clinical and research settings. Beside diagnosing PTSD a severity score can be calculated by summing up the scores of the 17 PDS symptom items that correspond to the three DSM-IV PTSD symptom clusters B, C, and D. Both the English and German versions have demonstrated excellent psychometric properties. In our sample, the internal consistency of the PDS total score was excellent with Cronbach's α=.91.

Socioeconomic Status: SES was calculated by means of a 6-point scale of paternal occupation and maternal education (range 2-12). Specific examples of educational and occupational levels were defined in a previous study (Largo, Molinari, Comenale, Weber, & Duc, 1989). Maternal education was used, because in Switzerland mothers often resign from their jobs and stay at home with young children. Three categories were defined: scores 2-5 as lower SES; scores 6-8 as middle SES; scores 9-12 as upper SES. This measure has been shown to be a reliable and valid indicator of SES in the Swiss community (Landolt, Vollrath, et al., 2002).

Medical variables: The pediatric oncologist answered questions on the type and time of diagnosis, treatment components, and the current status of treatment. Also, she rated several treatment-related variables. First, treatment intensity was rated on a 3-point Likert scale, with 1 = low: surgery only or six months chemotherapy or both, with a favorable prognosis (e.g., Hodgkin disease); 2 = medium: treatment > 6 months according to the treatment protocol, with an intermediate prognosis (e.g., osteosarcoma); 3 = high: treatment according to high-risk protocols, bone marrow transplantation, with an unfavorable prognosis (e.g., high-risk leukemia). Second, the pediatric oncologist in charge was asked to rate medical complications in each patient using a 3-point Likert severity scale: 0 = no complications; 1 = moderate complications (e.g., hospitalization due to infection), 2 = severe complications (e.g., multiple hospitalizations due to infections, no response to treatment). Third, information on treatment impact on daily functioning (e.g., play, motor activities) was rated on a 5-point Likert severity scale: 0 = no impact, 1 = small impact, 2 = moderate impact, 3=strong impact, 4=very severe impact. Fourth, information on functional status (FS), with regard to physical activities of

daily life, was rated using a 3-point Likert severity scale: 0 = good FS, 1 = moderate FS (e.g., marked fatigue, pain), 2 = poor FS (e.g., intense pain, considerable physical impairment). These measures have been successfully used in a previous study among children with cancer (Landolt, Vollrath, Niggli, Gnehm, & Sennhauser, 2006), but there are no available reliability and validity data for this rating system. Finally, the variable cumulative days of hospital stay was calculated by summing all days the child was hospitalized between time of diagnosis and time of assessment.

4.3 Statistical analysis

Data were analyzed using PASW Statistics 18 (SPSS Inc., Chicago, Illinois). Analyses were performed with two-sided tests, with $p<.05$ considered significant. Differences between participants and non-participants were determined by means of Mann-Whitney U tests. Descriptive statistics were used to analyze the frequency of PTSD symptoms and diagnosis. Previous to multivariate analysis, univariate analyses were conducted using the Spearman correlation test to identify predictors associated with full or partial PTSD in the child. To investigate the odds of having a full or partial PTSD diagnosis, a multivariate logistic regression model was constructed, including those variables with the most significant correlations ($p<.01$) in the univariate analyses.

4.4 Results

4.4.1 Sample Characteristics

Descriptive information about the sample is contained in Table 8. Boys were over-represented in our sample which is consistent with findings of international cancer registries (Mitter et al., 2011). Most families were from the middle or upper class, probably on account of the language requirement (many non-Swiss nationals are of lower SES). At diagnosis, 22 children (45.8%) were between 0 and 18 months, and 26 children (54.2%) were between 19 and 48 months. The children had the following diagnoses: malignant solid tumors (43%), leukemia (25%), malignant brain tumors (17%) and lymphomas or other cancer diagnoses (15%). At assessment, 21 (43.8%) of the children were still being treated, but none of them was hospitalized. Overall, 85.4% of the children had been treated with chemotherapy, 56.2% had had a surgical intervention, 16.7% had received radiation therapy, and 12.5% had undergone bone-marrow transplantation.

Table 8 Characteristics of the sample (n=48)

Age at assessment (months)	
Mean (SD)	34.8 (11.0)
Range	8-48
Gender	
Female	35.4% (17)
Male	64.6% (31)
Socioeconomic status	
Low	4.2% (2)
Medium	64.6% (31)
High	29.2% (14)
Unknown	2.1% (1)
Nationality	
Swiss	79.2% (38)
Other	18.8% (9)
Unknown	2.1% (1)
Age at diagnosis (months)	
Mean (SD)	18.7 (11.7)
Range	0-44
Time since diagnosis (months)	
Mean (SD)	15.6 (9.6)
Range	3-39
Treatment intensity	
Low	27.1%
Medium	50.0%
High	22.9%
Complications during	
No	31.3%
Moderate	58.3%
Severe	10.4%
Treatment impact on daily functioning	
No impact	12.5%
Slight impact	43.8%
Moderate impact	31.2%
Severe impact	12.5%
Current functional status	
Good	60.4%
Moderate	37.5%
Poor	2.1%
Cumulative days of hospital stay	
Mean (SD)	53 (43.1)
Range	3-173
Maternal PTSD	42.1% (16/38)

4.4.2 Presence of Full or Partial PTSD and PTSD Symptoms

Posttraumatic stress symptoms are listed in Table 9. Of the 48 children in the study, nine (18.8%) met full criteria for a diagnosis of current PTSD, based upon the alternative algorithm for young children (Scheeringa, 2011b). Notably, none of the children (0%) met the original DSM-IV criteria for PTSD. In addition, 20 children (41.7%) met criteria for partial PTSD. In the age group of children younger than 18 months at diagnosis, four children (20%) exhibited full or partial PTSD. In the age group of children older than 18 months at diagnosis, 16 children (80%) were diagnosed with full or partial PTSD.

Table 9 PTSD symptoms and diagnosis in children (n=48)

Reexperiencing	
% according to alternative algorithm	85.4
% according to DSM-IV algorithm	85.4
Mean symptom severity (SD)	.41 (.35) (range 1-2)
Avoidance/psychic numbing	
% according to alternative algorithm	62.5
% according to DSM-IV algorithm	2.1
Mean symptom severity (SD)	.22 (.24) (range 1-2)
Hyperarousal	
% according to alternative algorithm	22.9
% according to DSM-IV algorithm	22.9
Mean symptom severity (SD)	.25 (.31) (range 1-2)
All symptom clusters	
% according to alternative algorithm	18.8
% according to DSM-IV algorithm	0
% according to algorithm for partial PTSD	41.7
Mean symptom severity (SD)	.31 (.24) (range 1-2)

4.4.3 Determinants of PTSD

On univariate analysis, the diagnosis of full or partial PTSD correlated positively with child age at diagnosis (r=.47), treatment impact on daily functioning (r=.41), and maternal PTSD severity (r=.46) (all $p<.01$). Furthermore, shorter time since diagnosis (r=-.35), shorter time since the end of treatment (r=-.46), more medical complications (r=.36) and poor functional

status (r=.33) were significantly associated with more full or partial PTSD diagnoses (all p<.05). Female sex, age at assessment, SES, Swiss nationality, still being on active treatment, having a brain tumor, treatment intensity, and cumulative days of hospital stay were not significantly related to adverse outcomes in our sample.

Odds ratios for full or partial PTSD in children are presented in Table 10. Regression analysis revealed that time since diagnosis and treatment-related variables failed to demonstrate any increased probability of full or partial PTSD. On the other hand, higher child age at diagnosis (OR=1.11) and more severe maternal PTSD symptoms (OR=1.14) were associated with an increased probability of full or partial PTSD in the children. None of these variables could significantly predict the diagnosis of the re-experiencing, the avoidance and the hyperarousal symptom cluster (data not shown).

Table 10 Summary of logistic regression predicting full or partial PTSD in children (n=43)

	Child's full/partial PTSD				
	B	**SE**	**Odds ratio**	**95% conficence interval**	**Wald statistic**
Age at diagnosis (months)	.11	.05	1.11	1.01-1.23	4.28*
Time since diagnosis (months)	-.03	.07	.97	.86-1.10	.24
Medical complications	-.75	1.33	.47	.04-6.34	.32
Treatment impact on child's daily functioning	1.29	1.13	3.64	.40-33.44	1.31
Child's functional status	.58	1.43	1.78	.11-29.52	.16
Severity of maternal PTSD symptoms	.14	.07	1.14	1.01-1.30	4.28*

*p<.01

4.5 Discussion

This study is the first to report valid PTSD rates in infants and preschoolers with cancer. In support of our hypothesis, we found that 18.8% of the children met the age-appropriate PTSD criteria developed by Scheeringa et al. (Scheeringa et al., 2003). This is well within the range (10% to 21%) reported for older children with cancer (Butler et al., 1996; Landolt et al., 2003;

Currier et al., 2009). Moreover, this finding is in line with figures previously reported for PTSD in preschoolers after traumatic injuries like motor vehicle accidents (14.3%) (Meiser-Stedman et al., 2008) or burn injuries (13.2%) (Graf et al., 2011). Further studies on the impact of mass trauma, such as terrorism (DeVoe et al., 2006) or Hurricanes (Scheeringa & Zeanah, 2008), have identified prevalence rates between 17% and 50% among preschoolers. The high rate in the latter study can be partially explained by the nature of the self-selected sample and the exclusion of children < three years of age. However, in all these studies, it can be assumed that PTSD prevalences would have been considerably lower if the unmodified DSM-IV criteria and algorithm had been applied. In the meantime, there is strong evidence that using developmentally-sensitive instruments facilitates the accurate diagnosis of PTSD in young children (Scheeringa et al., 2003, 2005; Scheeringa, Wright, et al., 2006; Meiser-Stedman et al., 2008). Therefore, preliminary drafts of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (www.dsm5.org) provide a PTSD preschool subtype, which contains modified criteria and an alternative diagnostic algorithm (Scheeringa, Zeanah, et al., 2011).

In addition, this study provides data on various determinants of PTSD in children. Contrary to our a priori assumption, girls did not have an elevated risk to develop PTSD. However, the logistic regression model indicates two significant risk factors: child age at diagnosis and maternal PTSD. As an individual characteristic, higher child age at diagnosis was associated with an increased probability for developing PTSD. A possible explanation could be that the development of autobiographical memory from the age of 18 months onwards renders health-related fears more stable (De Young, Kenardy, & Cobham, 2011a). At the same time, it is reported to be more difficult for preschoolers to understand why they must come to the hospital, have procedures, and take medication (Kazak & Baxt, 2007). This could explain the developmental window from 18 to 48 months identified by Scheeringa and Zeanah (Scheeringa & Zeanah, 1995), during which children are particularly vulnerable to re-experiencing symptoms. Younger age might have acted as a protective factor because cognitive and developmental limitations shielded children from understanding what was happening to them. However, the finding might also represent an artefact of the limitations of assessing younger children. Younger children's symptoms could have been less apparent to their caregivers because of their developmental limitations in expressive and language capacities. The few studies that exist have yielded inconsistent findings regarding age at diagnosis as a predictor of PTSD in preschoolers (De Young et al., 2011a).

In line with our hypothesis, parameters related to an increased illness and/or treatment severity did not significantly predict PTSD. This is in line with several studies in older children with cancer (Bruce, 2006). Like in our study, objective treatment intensity was usually measured by the oncologist's assessment. Based on previous studies in older children the subjective appraisal of life threat and treatment intensity might be more important than objective medical characteristics. However, appraisal cannot be assessed reliably in very young children.

Regarding parent-related characteristics, we found that the severity of maternal PTSD was associated with a significantly higher probability of child's PTSD (OR=1.14). This finding is in line with our hypothesis and with the often-documented association between parent and child psychopathology after trauma (De Young et al., 2011a). Parents of children with a life-threatening illness witness the traumatic experiences of their children and are thereby prone to develop own PTSD symptomatology. Previous studies on preschoolers suggest that symptomatic mothers may have a limited capacity to provide a stress-buffer for their children (Stoddard, Saxe, et al., 2006). This could be harmful, since young children often rely fully on their caregivers to cope with stress and threats (Scheeringa & Zeanah, 2001). However, any presumed direct pathway from maternal to child symptomatology remains speculative, since there is no controlled evidence that can substantiate that parental PTSD affects children directly. Findings from a review study suggest a moderating influence of the child-parent relationship on child's PTSD and offer the construct of relational PTSD (Scheeringa & Zeanah, 2001). However, data on concurrent PTSD in children and parents is either cross-sectional or failed to measure the actual parent-child relationship and interaction patterns. The first study that applied an observational rating of parenting in relation to domestic violence failed to uncover any relationship between maternal warmth and child outcomes on the Child Behavior Checklist (Levendosky & Graham-Bermann, 2000). Observational data from a recent study revealed that those mothers who were the most symptomatic with PTSD and had the children who were the most symptomatic with PTSD exhibited the best emotional responsiveness (Scheeringa, 2011a). In conclusion, the direction of the effect of parent-child relationship and children's symptomatology is still unknown.

Some limitations of this study may have influenced the reported findings. First, our sample was relatively small, thereby reducing statistical power. Therefore, important research issues like different symptom clusters or different predictors in children younger versus older than 18 months at diagnosis could not be answered. Second, our sample is quite heterogeneous in terms of time since diagnosis. However, when controlled for other variables, time since

diagnosis did not significantly increase the probability of child's PTSD in the regression analysis. Third, due to the study's cross-sectional design, caution is warranted interpreting any causal relationships between outcome and predictor variables. Fourth, data gleaned from parental responses provide select information. Since children's symptoms were rated by mothers, possible influence of maternal distress on the perception of their child's symptoms must be entertained. However, other studies have quantified this limitation in young children with traumatic experiences by collecting self-reports from older children and parental reports, and the rates of PTSD were much higher when child and parent reports were combined. Younger children with similar types of trauma were included in both studies, which provided a reasonable estimate of how much parent report alone underestimates symptomatology (Scheeringa, Wright, et al., 2006; Meiser-Stedman et al., 2008). Finally, participants from lower SES were underrepresented in our sample, probably because we only enrolled parents who could speak German fluently.

Despite these limitations, our study provides crucial information on PTSD and its determinants in infants and preschoolers with cancer. This has several implications with respect to the clinical care of young children with cancer. First, our findings confirm the need for careful, developmentally-sensitive evaluations of PTSD in young pediatric cancer patients and their parents. Meanwhile, an updated interview has been integrated into the Diagnostic Infant Preschool Assessment (DIPA) (Scheeringa & Haslett, 2010). The DIPA presents empirically-validated developmental modifications of the symptoms for 13 DSM-IV disorders, including PTSD. Second, considering the child's age at diagnosis and the psychological adjustment of mothers might help to identify those children at greatest risk for psychological maladjustment. It is beyond the scope of this study, and therefore speculative for us to present strategies to prevent the development of PTSD in young children with cancer. Nonetheless, it makes sense to: 1) reduce exposure to the traumatic elements of treatment as much as possible (e.g., optimize pain management); 2) increase the child's feelings of security (e.g., by allowing parents to room-in); and 3) address physical health problems after treatment ends (e.g., rehabilitative options) (Kazak & Baxt, 2007). Finally, interventions that target the mothers' own distress may improve young children's psychological adjustment to cancer and its treatment.

5

General Discussion

In this chapter, the key findings of this thesis are summarized briefly, followed by a general discussion of the results. Limitations of this research are discussed and directions for further research are outlined. The chapter ends with implications for clinical practice and care.

Preschoolers are disproportionately exposed to paediatric injury and illness, relative to older children. Psychological responses to adverse and life-threatening medical events have been broadly studied in school-age children and adolescents. A growing body of research literature reports posttraumatic stress symptoms (PTSS) in the majority of patients and their parents at some point during and/or after medical treatment, and posttraumatic stress disorder (PTSD) as the most clearly established disorder following paediatric injuries and severe illness (Stoddard & Saxe, 2001; Bruce, 2006). Despite the fact that infants and preschoolers comprise a relatively large segment of paediatric patients, investigation of infant and preschooler mental health during and after traumatic medical events has largely been neglected. A long-held misconception that young children are not affected or recover quickly after stressful experiences has restricted scientific attention towards the very youngest paediatric patients (Liebermann et al., 2011). This research gap is profound, given that early childhood is an especially vulnerable period of life. Infants and preschoolers experience dynamic and rapid processes of development; they have limited coping skills; and they are highly dependent upon their primary caregivers concerning their physical and emotional wellbeing. Furthermore, early childhood is characterized as a period of neuroplasticity, in which the structure and function of the central nervous system are especially sensitive to environmental influences (De Young et al., 2011a). Fortunately, the importance of early childhood mental health and its potential ramifications for development have now been recognized. Over the last two decades, a small number of researchers and clinicians have started to work with traumatized young children, mostly children who have witnessed domestic violence or mass trauma, like natural disasters, or who have been sexually abused (Scheeringa & Zeanah,

1995). This research group eventually proposed developmentally-sensitive diagnostic criteria for PTSD, as well as an alternative diagnostic algorithm. This development now facilitates much needed research on infants' and preschoolers' psychological responses to various traumatic experiences.

The present thesis is positioned within this field of research, and aimed at expanding investigation on infant and preschooler mental health to the field of medical traumatic stress, while using the most contemporary assessment tool. Severe burns and cancer both are conditions which affect young children disproportionately often and can be particularly traumatic. Both conditions can be life-threatening, may involve invasive medical procedures, recurrent hospitalizations, and strict adherence to complex treatment regimens, and can permanently impact functional status and long-standing distress for both child and family. The review of research literature indicates that school age children are at risk for a range of adverse psychological consequences after severe burns or receiving a diagnosis of cancer (Section 1, Chapter 2.1). However, very few studies have included preschool children.

Shortly after having developed the research questions for this project, initial data on acute stress symptoms and their determinants in preschoolers with burn injuries were published by Stoddard et al. Thanks to the additional and more recent publication on PTSD in young children with burns (De Young et al., 2012), our data on burn injured infants and preschoolers now contribute to a growing body of scientific and clinical knowledge. However, within the field of early childhood cancer, our study provides the only published data on posttraumatic stress reactions, to date.

Before conducting two empirical studies on different groups of young paediatric patients, we reviewed the research literature on posttraumatic stress in early childhood (Section 2). This overview emphasized specific developmental issues and associated challenges with assessing PTSD in infants and preschoolers. The results of this review were helpful in determining the focus of the subsequent empirical investigations and in sensitizing us to special challenges in the assessment of mental health problems in very young children. Posttraumatic stress symptoms and behavioral problems were then assessed in a sample of young paediatric burn patients (Section 3) and in a sample of young paediatric cancer patients (Section 4).

5.1 Summary of Findings

Table 11 summarizes the main findings of the overview and the two empirical studies. The initial overview revealed a considerable gap in systematic research conducted on posttraumatic stress responses in infants and preschoolers. However, preliminary research evidence and clinical experiences indicate that preschoolers react to trauma very similarly to older children, and develop PTSD symptoms within the classic symptom cluster of re-experiencing, avoidance/numbing, and hyper-arousal. The existence of a developmentally-sensitive and behaviorally-anchored diagnostic interview to assess PTSD symptoms and the proposal of an alternative PTSD diagnostic algorithm for infants and preschoolers are novelties that have, therefore, only started to be applied for research purposes within the last decade. Our review recognized the following needs for ongoing research: 1) the research focus should extend to different groups of traumatized infants and preschoolers; 2) prospective studies are necessary to examine the course of PTSD and its impact throughout childhood and later life; and 3) investigating potential influencing factors and their interplay is not only important for research purposes, but also for clinical care.

Hereafter, the two empirical studies revealed that preschoolers with burn injuries and those with cancer experience considerable rates of PTSD when assessed with the above-mentioned diagnostic interview. Comparable with other findings in preschool children, avoidance/numbing symptoms are less frequent in very young children versus older children and adolescents. Behavioral problems of burn-injured preschoolers were within the normal range. Behavioral problems in young cancer patients also were assessed, but these results are not the subject of this thesis. However, the rate of internalizing problem behaviors was elevated in young children with cancer. Specific analysis showed that this elevated rate was mostly due to greater problems in the subscale *somatic complaints*. In the context of chronic disease, this finding is strongly presumed to be an artefact. Finally, maternal PTSD was determined to be an influencing factor for child's PTSD in both samples. Another family-related and one child-related factor were found to be associated with children's psychological outcomes. Notably, medical characteristics were not significantly related to a child's PTSD or problem behaviors.

Table 11 Summary of main findings of the three studies

Authors / Content	Method	Main findings
Graf, Irblich & Landolt, 2008 *Section 2*	Descriptive overview	• Infants and preschoolers show similar traumatic stress reactions within the same PTSD symptom clusters as older children • Frequency of PTSD after mixed traumatic events as high as 30% • Existence of developmentally-sensitive PTSD diagnostic criteria in a diagnostic interview • Adjustment of the PTSD diagnostic algorithm for diagnosis in early childhood • Significant research deficit in retrospective and prospective studies implementing the developmentally-sensitive PTSD criteria in infants and preschoolers • Significant research deficit considering predictive factors of PTSD in early childhood
Graf, Schiestl & Landolt, 2011 *Section 3*	Semi-structured interview Questionnaires Statistical analysis	• **Burn sample** • N=76 • Mean age: 32 months (SD=9.5; range 12-49) • Frequency of PTSD: 13.2% • Normal rates of behavioral problems • Correlates of child's PTSD: maternal PTSD, quality of family relationships
Graf, Bergstraesser & Landolt, 2012 *Section 4*	Semi-structured interview Questionnaires Statistical analysis	• **Cancer sample** • N=48 • Mean age: 34.8 months (SD=11; range 8-48) • Frequency of PTSD: 18.8% • Predictors of child PTSD: higher child age at diagnosis, maternal PTSD

5.2 Reflections on the Findings

Consistent with the research hypothesis, children in our studies presented with a similar frequency rate of PTSD as seen in research on older paediatric patients (between 10% and 20%). Moreover, our findings are in line with the small body of research on PTSD frequency rates in *injured preschoolers* (between 10% and 15%). In the field of *severely ill preschoolers*, our study is the first to report valid frequency rates for this age group and, therefore, lacks any direct comparisons. Although the prevalence rate we identified was slightly higher in our cancer than burn sample, this difference was not statistically significant. Across the total sample of 124 infants and preschoolers with either one of these conditions, the frequency rate of PTSD was 15.3% on average, 15 months after a burn injury or cancer

diagnosis. Contrary to findings in traumatized school-age children, adolescents and adults and despite the lowered diagnostic threshold, avoidant symptoms were less frequent than reexperiencing symptoms. This finding replicates earlier evidence in infants and preschoolers after traumatic experiences (Levendosky et al., 2002; Meiser-Stedman et al., 2008) and might reflect developmental differences in the expression of PTSD symptoms. Young children possible respond to trauma by clinging to their caregivers rather than intensively avoiding trauma-related stimuli. However, many of the avoidant symptoms are highly internalizing phenomena and difficult to detect - despite their developmentally sensitive modification. Either way, avoidant symptoms might be less reflective of trauma in early childhood compared to later childhood and adolescence (Levendosky et al., 2002).

In summary, the majority of the investigated young children did not develop posttraumatic stress disorders after medical traumatic stress. However, burn injuries, cancer and medical treatment experiences can have a negative psychological impact on a significant minority of infants and preschoolers. Findings like these are of great relevance, since early stressful experiences and adversities have been shown to affect the development of a body's stress response system, as well as the developing brain, and may cause lifelong impairment in both physical and mental health if undetected or left untreated (Shonkoff & Garner, 2012).

According to the pathogenetic models outlined in Section 1, Chapter 1.3, psychological adjustment is a dynamic process influenced by characteristics of the child, the trauma and the environment.

Child characteristics

Among the child characteristics investigated in these studies, higher age at diagnosis was the only factor considered to increase the risk of PTSD in young children with cancer; 80% of the children diagnosed with PTSD were older than 18 months at the time of diagnosis. The few studies that exist have yielded inconsistent findings regarding age as a predictor of PTSD in preschoolers (De Young et al., 2011a). Children younger than 18 months may not have perceived the threat posed by their medical condition and, therefore, might have been protected from the impact of trauma. The relative lack of PTSD in children under 18 months old also could be explained by the development of autobiographical memory from the age of 18 months onwards. In children older than 18 months, traumatic events can be represented verbally and, thereby, be more detailed and durable (Salmon & Bryant, 2002). Scheeringa and Zeanah (1995) identified a developmental window from 18 to 48 months, during which

children are particularly vulnerable to re-experiencing symptoms. It can be assumed that children older than 18 months have a more detailed and durable mental representation of trauma, but have limited capacities to control their mental and emotional processes, since emotion regulation, social cognition, memory, language and conversation are only just developing (Salmon & Bryant, 2002). Although these findings require replication, it can be speculated that preschoolers are especially vulnerable to PTSD relative to younger children. However, younger children's symptoms could have been less apparent to their caregivers because of their developmental limitations and, therefore, the finding of less PTSD in the youngest infants also might be an artefact of the limitations of assessing children younger than 18 months using the PTSDSSI.

Medical characteristics

Contrary to our initial hypothesis, medical characteristics did not significantly influence the development of PTSD. Previous studies have shown that frequency and severity of PTSD vary by the type of trauma and by the extent of exposure. Exposure to family violence or to highly intensive traumatic events related to the Wold Trade Centre attack seem to be associated to more PTSD symptoms and behavioral problems than accidental injuries (Chemtob, Nomura, & Abramovitz, 2008; Graham-Bermann et al., 2008). Furthermore, threat to a caregiver was among the strongest predictors of PTSD in young children (Scheeringa & Zeanah, 1995; Scheeringa, Wright, et al., 2006). In the context of medical trauma, caregivers usually engage in extensive parental care and attention, what might buffer the traumatic impact of injury, severe illness and treatment.

As discussed in the Sections 3 and 4, the subjective appraisal of life-threatening conditions and treatments seems to be more important for the development of PTSD than objective markers of trauma severity. Although included in all pathogenetic models presented in Section 1, little is empirically known about the subjective appraisal of preschool aged children during traumatic exposures. However, the few existing studies show a consistent and strong influence of subjective appraisal of life-threat and treatment intensity, as well as illness beliefs on school-age children's PTSD after cancer (Taieb et al., 2003) and accidents (Stallard, Velleman, & Baldwin, 1998). Although there is empirical and clinical evidence that the appreciation of life threat depends on a child's cognitive developmental stage and that the concept of death as permanent is not stable in young children (Stuber, Nader, Houskamp, & Pynoos, 1996), several other aspects of severe injury and illness possibly induce traumatic stress in young children. For example, older paediatric cancer patients in the above-mentioned

study indicated the perceived life-threat of diagnosis and treatment as their worst moments, whereas younger children around 8 years of age mentioned medical procedures as their worst moments. In our sample of infants and preschoolers with cancer, we have identified older age as a risk factor for child PTSD. This finding potentially supports the role of emerging subjective appraisal in the pathogenesis of PTSD, even among very young children. However, the question of how to operationalize and reliably assess subjective appraisal at the time of traumatic exposure remains a challenge in school-age children, and is mostly unanswered for younger children. One possible direction, via the observation of behavior and physiology, was initiate by Scheeringa et al. in traumatized and non-traumatized young children (Scheeringa et al., 2004) as well as Stoddard et al. in their investigation on acute stress responses of young children with burns (Stoddard, Ronfeldt, et al., 2006) and represents a challenge for future research.

Family-related characteristics

Consistent with our research hypothesis, we identified some influence of family-related characteristics, particularly maternal PTSD in both our burn and cancer samples, and the quality of family relationships in the burn sample. These findings were discussed broadly in Sections 3 and 4. An association between child outcomes and maternal PTSD has been consistently demonstrated in previous research on young children after various traumatic events (Laor et al., 1997; Laor, Wolmer, & Cohen, 2001; Bogat et al., 2006; Stoddard, Saxe, et al., 2006; Scheeringa & Zeanah, 2008; Nomura & Chemtob, 2009; Feldman & Vengrober, 2011). However, caution is certainly warranted when interpreting the association between parental and child PTSD. Because caregivers are so central to the emotional lives of infants and preschoolers, traumatic events almost invariably affect both child and caregiver, and may involve complex changes and adaptations in the caregiver-child relationship (Levendosky et al., 2002). The relational PTSD model proposed by Scheeringa and Zeanah (2001) (see Section 1, Chapter 1.4) describes three specific patterns of association between a child's and caregiver's PTSD symptoms (Scheeringa & Zeanah, 2001). (1) Parents' own PTSD symptoms might limit their ability to read and accurately respond to their child's symptomatology. (2) Parental over-protectiveness might occur as a response to traumatisation, and lead to changes in parenting style. (3) Constant preoccupation of the parents with traumatic reminders might have a re-traumatizing effect on their young child (Scheeringa & Zeanah, 2001). These relational PTSD patterns emphasize the unique importance of the nature and quality of the child-caregiver relationship in the context of early

childhood trauma. However, these patterns, as well as other effects, are not yet sufficiently studied. A few studies have investigated the potential mediating role of maternal PTSD on child outcomes. For example, among Israeli preschoolers, avoidance in a mother was found to strongly predict a child's PTSD symptoms 30 months after scud missile attacks (Laor et al., 1997). This finding of maternal stress-buffering leading to stress exacerbation was replicated in a later study: children with reduced PTSD symptoms five years after the missile attacks were more likely to have mothers who were functioning well (Laor et al., 2001). Consistent with this, fewer maternal PTSD symptoms were associated with greater maternal sensitivity towards their child (Feldman & Vengrober, 2011). In the context of medical trauma, parental distress has been shown to mediate the relationship between a child's levels of pain and acute stress symptoms after burn injuries (Stoddard, Ronfeldt, et al., 2006). Similarly, maternal PTSD symptoms have been demonstrated to predict infants' poor emotion regulation, operationalized as an impaired ability to recover from distress and arousal (Bosquet Enlow et al., 2011). Similar findings have been demonstrated by Feldman & Vengrober (2011). Mothers of exposed children without PTSD provided more sensitive containment when their child expressed distress during trauma evocation. On the other hand, observational data from a recent study revealed that the most symptomatic mothers who had the most symptomatic children exhibited the best emotional responsiveness (Scheeringa, 2011a). In conclusion, the type and course of associations between concurrent PTSD remain unknown. Most data are either cross-sectional in nature or have failed to measure actual parent-child relationships and interaction patterns. Prospective investigations must clarify this picture.

5.3 Strengths and Limitations

There are several strengths of this research. The two empirical studies benefited from relatively homogenous samples of children treated under the same institutional conditions, from good retention rates, from the utilisation of a developmentally-sensitive diagnostic interview and psychometrically-sound assessment measures, and at least partly from the inclusion of fathers. Finally, the research addressed clinically relevant questions and the collected information is of practical use for mental health, medical and research professionals.

One the other hand, certain limitations of this study may have influenced the reported findings. First, due to the study's cross-sectional design, interpretation of any relationships between outcome and predictor variables warrants caution. Second, the sample sizes were

relatively small and, consequently, statistical power was reduced. Therefore, further important research questions such as different predictors in separate age groups or for specific symptom clusters could not be addressed within our study. Third, given the wide range of time since diagnosis, our sample is quite heterogeneous concerning this matter. However, when the influence of other variables was controlled during regression analysis within the cancer sample, time since diagnosis did not significantly predict child PTSD. Fourth, data gleaned from parental responses provide only select information. Since children's symptoms were rated by their mothers, the potential influence of maternal distress on the perception and rating of their child's symptoms must be entertained. This being said, this is an almost universal problem in research within the field of early childhood mental health. Some studies have quantified this limitation in young children with traumatic experiences by collecting self-reports from older children and parental reports. Rates of PTSD were much higher when child and parent reports were combined. Younger children with similar types of trauma were included in both studies, which provided a reasonable estimate of how much parent report alone underestimates symptomatology (Scheeringa, Wright, et al., 2006; Meiser-Stedman et al., 2008). In our studies, interviews were conducted face-to-face and parents were required to give examples of their children's symptoms before they were endorsed. Furthermore, although maternal PTSD rates were widely disparate between the two samples (42% maternal PTSD in the cancer sample, 6% maternal PTSD in the burn sample), children's PTSD rates were very similar across the two samples. Finally, participants from middle and upper SES were overrepresented in our samples, probably because we only enrolled parents who could speak German fluently. However, findings on the association between SES and the development of PTSD are inconsistent (Bruce, 2006), therefore a possible influence of this overrepresentation upon our findings cannot be determined.

5.4 Directions for Future Research

Development and validation of developmentally-appropriate assessment measures for PTSD needs to continue to establish diagnostic criteria, validity and factor structures. More research is needed to determine the prevalence, course, co-morbidity and determinants of PTSD in young children across a variety of trauma types. In the field of medical trauma, studies with a prospective design are needed, since adjustment is not static over the course of medical treatment. Moreover, longitudinal studies would be beneficial to establish course and relationship between child and parental PTSD, as well as to identify other risk and protective

factors, and their mechanisms. For example, the inclusion of physiological reactivity (e.g., heart rate, cortisol, crying, pain), parenting style, and attachment or interaction patterns could lead to increased knowledge regarding mediating influences. Finally, randomised trials could help to establish evidence-based screening, prevention and intervention strategies, as well as treatment strategies for the very youngest paediatric patients.

5.5 Clinical Implications of this Research Project

The two studies described herein have implications for the clinical care of young children with burn injuries and cancer. Our findings add to the recently-emerging evidence that even very young children develop long-lasting symptoms of PTSD after traumatic medical events. Therefore, the assessment of specific PTSD symptoms is especially relevant in young children after traumatic events, since common instruments such as the CBCL seem to underestimate young children's posttraumatic stress reactions. Our findings confirm the need for careful, developmentally-sensitive evaluations of PTSD in young paediatric patients and their parents. Meanwhile, preliminary drafts of the fifth edition of the DSM provide a PTSD preschool subtype which contains the modified criteria and the PTSD-AA (www.dsm5.org). Furthermore, an updated PTSD interview has been integrated into the Diagnostic Infant Preschool Assessment (DIPA) (Scheeringa & Haslett, 2010). The DIPA presents empirically validated developmental modifications of the symptoms for thirteen DSM-IV disorders, including PTSD. In a clinical setting, paediatricians should be aware of PTSD symptoms and should take a good history for emotional and behavioral problems. Especially the frequency, intensity and duration of symptoms, their pervasiveness across settings, and their effect on daily functioning are important aspects to differentiate between posttraumatic stress reactions and a wide range of normal preschool behavior (Carter, Briggs-Gowan, & Davis, 2004).

It is beyond the scope of this project, and therefore speculative for us to present strategies to prevent the development of PTSD in young children with burn injuries and cancer. Nonetheless, following the integrative model of paediatric medical traumatic stress (Section 1, Chapter, 1.3.4) it makes sense to: 1) reduce unnecessary exposure to the traumatic elements of the medical condition and its treatment as much as possible (e.g., optimize pain management); 2) increase the child's feelings of security (e.g., by allowing parents to room-in with them, by increasing the predictability and stability of daily routines, by allowing the parent-child dyad some control over aspects of medical treatment wherever possible, and by

listening to evaluate each child's understanding of events and possible misconceptions); 3) treat parental distress or PTSD; and 4) address physical health problems as traumatic reminders in the long-term, after treatment ends (e.g., rehabilitative options). In conclusion, the adaptation of a so-called *trauma-informed practice* in children's hospitals helps to raise understanding and awareness of traumatic stress and related responses, and enables health-care professionals to provide basic interventions to children and families, so as to minimize traumatic experiences and maximize the continuity of care (Kazak et al., 2006). With regard to the particular developmental risk after traumatic experiences in early childhood, vulnerable children have to be identified as early as possible and linked with specialized mental health services. On the basis of the growing recognition of trauma impact and prevalence in infants and preschoolers, age appropriate treatment approaches are now being developed and empirically tested (Scheeringa, Weems, Cohen, Amaya-Jackson, & Guthrie, 2011).

In conclusion, understanding posttraumatic stress responses of infants and young children with severe injuries and illnesses is of great importance in order to develop prevention and treatment strategies. Addressing mental health needs in this young paediatric population is very challenging due to rapid developmental changes in various domains. However, the continuative promotion of timely and effective interventions is particularly essential for a healthy adaptation after paediatric medical traumatic stress in early childhood.

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Appendix

Posttraumatic Stress Disorder Semi-Structured Interview and Observational Record for Infants and Young Children German-Version (PTSDSSI-D)

KINDERSPITAL ZÜRICH
Universitäts-Kinderkliniken · Eleonorenstiftung

Studie zur Lebensqualität und zum Befinden von Säuglingen und Kleinkindern mit Krebskrankheiten
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Posttraumatische Belastungsstörung – Semistrukturiertes Interview

und Beobachtungsbogen für Säuglinge und Kleinkinder

(M.S. Scheeringa & C.H. Zeanah, 1994, Version 1.4 2005)

(Übersetzt von D. Irblich, Hepton, & Landolt, 2006)

Kind:……

ID-Nummer:……

Datum:……

Befragte Person:……

InterviewerIn:……

Ort des Interview: ❒ zu Hause ❒ im Kinderspital

Die Fragen sollen der primären Betreuungsperson des Kindes gestellt werden. Der Interviewer stellt zunächst die vorgegebene Frage. Wenn diese bejaht wird, sind dafür Beispiele zu nennen. Nachfragen des Interviewers und Erklärungen der/des Befragten sollen zu einer möglichst großen Sicherheit bei der Entscheidung führen, ob ein Symptom tatsächlich vorhanden ist oder nicht.

Fragen Sie, ob die nachfolgenden Traumata zu irgendeinem Zeitpunkt im Leben des Kindes aufgetreten sind. Um als Trauma gewertet zu werden, muss das Ereignis zu ernster Verletzung bei dem Kind geführt haben oder das Kind muss potentiell verletzungsgefährdet gewesen sein oder es wurde Zeuge einer tatsächlichen oder potentiellen Verletzung einer geliebten Person. Das Kind…

1	…erlebte einen Auto-, Flugzeug- oder Schiffsunfall	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
2	…wurde von einem Tier angegriffen	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
3	…erlebte eine von Menschen verursachte Katastrophe (Unfall, Feuer, Krieg)	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
4	…erlebte eine Naturkatastrophe (Wirbelsturm, Hochwasser etc.)	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
5	…wurde Zeuge, wie eine andere Person geschlagen, vergewaltigt, ihr mit ernsthafter Schädigung gedroht, sie angeschossen, verwundet oder getötet wurde	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
6	…erlebte physische Misshandlung	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
7	…erlebte sexuelle Misshandlung, einen sexuellen Angriff oder Vergewaltigung	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
8	…erlebte einen Verbrennungsunfall	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
9	…ist beinahe ertrunken	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
10	…erlebte eine Krankenhauseinweisung, den Aufenthalt in einer Unfallambulanz, einen schwerwiegenden medizinischen Eingriff (Operationen, Injektionen etc.)	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
11	…erlebte eine Entführung	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:
12	…erlebte eine andere traumatische Erfahrung	Erstmaliges Auftreten Datum:	Häufigkeit: Zahl:	Letztmaliges Auftreten: Datum:

Wenn mehr als ein traumatisches Ereignis vorliegt, fragen Sie. „Welches dieser Ereignisse verursachte ihrer Meinung nach die meisten emotionalen und Verhaltensprobleme bei ihrem Kind?“ Notieren Sie Nummer 1 – 12.

Krebskrankheit und Behandlung

War Ihr Kind im letzten Monat hospitalisiert?

❒ 0 Nein

❒ 1 Ja

Falls Ja:

Grund:……
……

Dauer:……

Bei den folgenden Fragen erkundigen Sie sich nach dem erstmaligen Auftreten im Zusammenhang mit dem traumatischen Ereignis. Fall es sich um mehrere traumatische Ereignisse handelt, sprechen sie von „den Ereignissen“.

Kriterien der posttraumatischen Belastungsstörung

			Alternative Kriterien	DSM-IV Kriterien
1	**Ereignis, das auf der vorherigen Seite eingetragen wurde.**	**A.** (1) Das Individuum hat ein traumatisches Ereignis erlebt	0 1	0 1
2	**Wirkte Ihr Kind zu dem Zeitpunkt des Ereignisses sehr verängstigt oder hilflos oder war es auf irgendeine Art sehr verstört?**	(2) Die Reaktion des Kindes zeigte intensive Furcht, Hilflosigkeit, Entsetzen, aufgelöstes oder agitiertes Verhalten erkennen.		0 1 2

Nun möchte ich Sie fragen, wie Ihr Kind nach dem Ereignis reagierte. Zum Beispiel...	**B. Symptome des Wiedererlebens** (Alternative Kriterien und DSM-IV je mindestens 1)		
1	**...hat Ihr Kind jemals Teile des traumatischen Ereignisses nachgespielt?**	(1) Nachspielen des Traumas	0 1 2	0 1 2
	Notieren Sie, ob es (a) sich um spielerische Wiederholung oder (b) zwanghaftes, repetitives und monotones posttraumatisches Spiel handelt:			
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
2	**...hat Ihr Kind zu dem Ereignis wiederholt Aussagen gemacht oder Fragen gestellt? Wirkte es dadurch belastet?**	wiederholtes Erinnern an das Ereignis (Belastung wird für das alternative Symptom nicht verlangt)	0 1 2	0 1 2
	Notieren Sie, ob die Erinnerung das Kind quält oder nicht:			
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
3	**...hatte Ihr Kind Alpträume davon oder allgemein vermehrt Alpträume seit dem Ereignis?**	(2) Alpträume	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		

4	**...schien Ihr Kind Flashbacks zu haben; d. h. verhielt es sich für mindestens eine Minute so als passiere das traumatische Ereignis wieder?**	(3) Der Inhalt der Flashbacks ist bekannt und hat einen Bezug zum Trauma Die Episode hat objektive Merkmale eines Flashbacks	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
5	**…oder wirkte es wie in einem Dämmerzustand?**	Dissoziation	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
6	**...wirkte ihr Kind jemals sehr aufgeregt, weil es etwas gesehen oder gehört hatte, wodurch es an den Vorfall erinnert wurde?**	(4) Psychische Belastung, ausgelöst durch interne oder externe Erinnerungsreize an das Ereignis	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
7	**...wurde Ihr Kind durch eine Erinnerung an das Ereignis körperlich in Aufregung versetzt, hatte es z.B. einen schnellen Puls, sah zittrig aus oder atmete sehr schnell?**	(5) Physiologische Reaktionen, ausgelöst durch interne oder externe Erinnerungsreize an das Ereignis	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			

Seit dem Ereignis...	**C. Abflachung der Reagibilität und Vermeidung** (Alternative Kriterien mindestens 1; DSM-IV mindestens 3)		
1	**...hat ihr Kind versucht, Gespräche über das Ereignis zu vermeiden?**	(1) Vermeiden von Gedanken Gefühlen oder Gesprächen, die mit dem Trauma in Verbindung stehen	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
2	**...oder hat es versucht Orte, Personen oder Dinge zu meiden, die mit dem Ereignis zusammen hängen?**	(2) Vermeiden von Aktivitäten, Orten oder Personen, die mit dem Trauma assoziiert werden	0 1 2	0 1 2

	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
3	**...besteht bei Ihrem Kind eine Erinnerungslücke für wichtige Aspekte der traumatisierenden Situation?**	(3) Unfähigkeit, einen wichtigen Aspekt des Traumas zu erinnern		0 1 2
4	**...spielt Ihr Kind weniger als vorher?**	(4) Deutlich verringertes Interesse oder verminderte Teilnahme an bedeutsamen Aktivitäten Einschränkungen des Spielverhaltens	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
5	**...war ihr Kind mehr zurückgezogen und weniger gesellig als vorher?**	(5) Gefühle der Losgelöstheit oder Entfremdung von anderen Sozial mehr zurückgezogen	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
6	**...zeigte Ihr Kind weniger Gefühle als sonst?**	(6) Eingeschränkte Bandbreite des Affekts	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
7	**...erschien Ihr Kind Ihnen so, als gäbe es nichts in der Zukunft, worauf es sich freuen kann?**	(7) Gefühl einer verkürzten Zukunft		0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		

Seit dem Trauma...		**D. Symptome der Übererregung** (Alternative Kriterien und DSM-IV je mindestens 2)		
1	**...hatte Ihr Kind Schwierigkeiten ins Bett zu gehen oder einzuschlafen?**	(1) Nächtliches Aufwachen oder Schwierigkeiten einzuschlafen, die nicht mit einer Angst vor Alpträumen oder der Dunkelheit zusammenhängen	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
2	**...zeigte Ihr Kind eine erhöhte Reizbarkeit, war es schnell beunruhigt, hatte es starke Stimmungs-schwankungen oder Wutausbrüche?**	(2) Erhöhte Irritierbarkeit, Wutausbrüche Affektlabilität oder starke Wutausbrüche	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
3	**...hatte Ihr Kind größere Schwierigkeiten, sich auf Dinge zu konzentrieren als früher?**	(3) Verringerte Konzentration.	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
4	**...schien Ihr Kind übermäßig wachsam oder auf der Hut zu sein, obwohl es dafür keinen Grund gab?**	(4) Hypervigilanz	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
5	**...gab es Zeiten in denen ihr Kind erschrak oder sehr bestürzt war, wenn es ein plötzliches Geräusch hörte oder wenn sich ihm jemand von hinten unerwartet näherte?**	(5) Übertriebene Schreckreaktion	0 1 2	0 1 2
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		

		Assoziierte Symptome (Als Begleitsymptome relevant, für die Diagnose jedoch nicht erforderlich)		
1	**...hat Ihr Kind einige der Fertigkeiten verloren, die es vorher konnte? Hat es wieder eingenässt, verstummte es oder machte es sprachliche Rückschritte?**	(1) Verlust von bereits erworbenen Entwicklungsfertigkeiten, besonders sprachliche Rückschritte und sekundäre Inkontinenz.	0 1 2	
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
2	**...hat Ihr Kind Angst vor Dingen entwickelt vor denen es vorher keine hatte, wie z. B. Angst alleine zur Toilette zu gehen, vor Dunkelheit, vor Fremden oder anderen Dingen?**	(2) Neue Ängste	0 1 2	
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
3	**...brachte es Ihr Kind deutlich mehr aus der Fassung als vorher, wenn es sich von seiner Mutter trennen musste?**	(3) Neue Trennungsangst	0 1 2	
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		
4	**...war Ihr Kind viel aggressiver als früher?**	(4) Neue Aggression	0 1 2	
	Wann wurde das Verhalten erstmalig festgestellt?			
	Häufigkeit:	Dauer:		

	Dauer (Alternative Kriterien und DSM-IV je mindestens einen Monat)		
5	**Wurde Ihr Kind von den meisten dieser Dinge mindestens seit einem Monat beeinträchtigt?**	0 1	0 1

	Beeinträchtigungen und Belastungen (Alternative Kriterien und DSM-IV je mindestens 1)	
Nach allem was Sie mir berichtet haben, scheinen folgende Auffälligkeiten zu bestehen: *(Symptome aufzählen).* Jetzt werde ich Ihnen 5 weitere Fragen stellen, die sich darauf beziehen, inwieweit diese Verhaltensweisen den Alltag beeinträchtigen.		
1	Stehen diese Verhaltensweisen *(Symptome müssen eventuell erneut aufgezählt werden)* alltäglichen Abläufen im Familienleben im Weg? Verhindern diese z.B., dass das Kind mit der Familie etwas unternehmen kann, z. B. in ein Restaurant oder in ein Geschäft zu gehen, Ausflüge zu machen *(evtl. andere Beispiele benutzen)* oder werden dadurch Aktivitäten innerhalb des Hauses unmöglich gemacht, z.B. sich anzuziehen, aufzuräumen, zu baden oder Aktivitäten mit der Familie zu unternehmen, die Spass machen?	
	Die meiste Zeit	2
	Manchmal	1
	Selten oder nie	0
2	Wird Ihr Kind durch diese Verhaltensweisen *(Symptome müssen eventuell erneut aufgezählt werden)* davon abgehalten, mit anderen Kinder etwas gemeinsam zu machen, z.B. zu spielen, Freundschaften aufrecht zu erhalten, auswärts zu schlafen, Ausflüge zu machen *(eventuell andere Beispiele benutzen)*?	
	Die meiste Zeit	2
	Manchmal	1
	Selten oder nie	0
3	Wissen Sie, ob die Lehrer/Erzieher Ihres Kindes wegen dieser Verhaltensweisen *(Symptome müssen eventuell erneut aufgezählt werden),* in Stress geraten? Hat ein Lehrer/Erzieher jemals seit dem Trauma etwas darüber Ihnen gesagt, dass Ihr Kind Probleme in der Klasse/im Kindergarten macht?	
	Die meiste Zeit	2
	Manchmal	1
	Selten oder nie	0
	Nicht anwendbar	-9
4	Geraten Sie (als Bezugsperson des Kindes) wegen der Verhaltensweisen *(Symptome müssen eventuell erneut aufgezählt werden)* in Stress? Haben diese Symptome Auswirkungen auf die Zeit, die Sie mit Ihrem Kind verbringen?	
	Die meiste Zeit	2
	Manchmal	1
	Selten oder nie	0

5	Und zum Schluss: Glauben Sie, dass Ihr Kind wegen dieser Verhaltensweisen *(Symptome müssen eventuell erneut aufgezählt werden)* leidet? Fühlt es sich deswegen z. B. schlecht, denkt es schlecht über sich, weint es seither vermehrt oder wirkt sehr unglücklich?	
	Die meiste Zeit	2
	Manchmal	1
	Selten oder nie	0

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Curriculum vitae

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Education

2006 to 2013	Ph.D. studies in Psychology, University of Zurich, Switzerland
	Doctoral thesis: “Posttraumatic stress and behavior in injured and severely ill infants and preschoolers”
2007 to present	Postgraduate education in systemic psychotherapy, institute for psychotherapy of child- and adulthood in Bern; institute for systemic and solution-oriented therapy (wilob) in Lenzburg
2006	Licentiate with a major in psychology, and minors in psychopathology of childhood and adolescence, and social anthropology (equivalent to a MSc in Psychology) at the University Zurich, Switzerland.
	Master thesis (translation): “Quality of life and psychological adjustment in children and adolescents with neurofibromatosis type 1”
1998	Swiss federal maturity

Work experience

2009 to present	Clinical Psychologist, Department of Psychiatry and Psychosomatics and Department of Oncology, University Children’s Hospital Zurich, Switzerland

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